

The Diagnostic Process in Bipolar Disorder: A Service User Perspective

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**Thesis submitted in partial fulfilment of the requirement for the degree of
Doctor of Clinical Psychology at the University of Wales, Cardiff and South
Wales Doctoral Course in Clinical Psychology**

DECLARATION

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

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ABSTRACT

Bipolar disorder is a severe and enduring mental health condition. Although early identification is associated with better outcomes, research has shown that many people wait over a decade after first experiencing affective symptoms before a correct diagnosis is made. A misdiagnosis of unipolar depression often leads to the inappropriate prescription of potentially mood-destabilising antidepressant medications. The aim of this study was to consider service user and carer experiences and their often overlooked views on diagnostic issues.

Participants were recruited via the charity Bipolar UK. Initially a focus group discussed the diagnostic process and relevant issues, then the transcript was analysed thematically and used to develop a detailed survey questionnaire. The survey was piloted before being launched online and completed by 262 service users and 65 carers.

Survey respondents reported an average delay of over eleven years between first seeking help for bipolar symptoms and being correctly diagnosed. Almost 70% reported a previous misdiagnosis of depression, and over half had experienced mania/hypomania whilst taking antidepressant medication. Nearly a third consulted a doctor over 20 times with bipolar symptoms before receiving help for bipolar disorder. Participants considered that improvements are needed in primary care mental health assessment and that GPs need more training. Many reported that their condition had led them to be discriminated against and agreed that society's lack of understanding was a major problem. Carers indicated similar opinions and emphasised the potential benefits of including carers in the assessment process.

This study suggests that the identification of bipolar disorder is often poor and that assessment of the condition in primary care needs to be improved. Service users offered suggestions for improvements, including recognition of early indicators, appropriate assessment questions and better training which could be adopted by service providers. Limitations of the study and implications for future research were discussed.

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CHAPTER 1 - INTRODUCTION

1.0 OVERVIEW

Bipolar disorder is a chronic and often disabling mental health condition. It can have a considerable impact on quality of life for those who experience it, as well as presenting significant costs to services and society (Kessler *et al.*, 2007). Pathways to diagnosis and the diagnosis itself have recently been the subject of much controversy and scrutiny (Angst, 2007; Chan & Sireling, 2010; Joyce, 2008; Nusslock & Frank, 2011; Zimmerman, 2010). Research has shown that one issue is delayed diagnosis; many people can wait up to twelve years after first experiencing affective symptoms before a correct diagnosis of bipolar disorder is made (Berk *et al.*, 2007). Alternative diagnoses may precede this, including ADHD, borderline personality disorder and, most frequently in primary care, unipolar depression (Ghaemi *et al.*, 2002; Smith *et al.*, 2011). Depression is typically treated with antidepressant medication, which can be ineffective or potentially harmful for those with a bipolar presentation (Goodwin, 2009; Rybakowski, 2011). It is also recognised that the earlier bipolar disorder is identified, the better the treatment outcomes and long-term prognosis (Hirschfeld *et al.*, 2003). This delay in recognition of bipolar symptoms therefore presents considerable concerns to both service users and services. Screening tools could be helpful, but those that are available are deemed inadequate or too lengthy for routine use in busy clinical settings (Allen & Smith, 2008). There is also a varied literature on other indicators of bipolar disorder which are not part of current diagnostic criteria, such as family history and markers of atypical depression (Bowden, 2005). However, many potentially relevant questions may not be currently asked by clinicians.

The literature on bipolar diagnosis is generally written from a service provider, clinician and researcher point of view (BPS, 2010), and, with a few exceptions (e.g. Hirschfeld *et al.*, 2003), usually does not consider the perspective and opinions of service users or carers, and is even less likely to include service user views in the planning stages of the research (Telford & Faulkner, 2004). This study therefore intended to firstly consult a service user focus group regarding the development of an online survey. The survey aimed to investigate people's experience of being diagnosed with bipolar disorder, to consider whether the issues described in the published literature were accurate from a service user perspective, and if so, to ask service users why they consider the problems exist and how the process of diagnosis could be improved. It also aimed to take into account the often overlooked views of carers (Foster, 2010).

1.1 LITERATURE REVIEW OUTLINE

A systematic literature search was carried out to review the large body of research related to the diagnosis of bipolar disorder. This involved a number of stages, initially focusing on general topics relevant to bipolar diagnosis, then narrowing down to consider more specific problematic issues which have been identified in the research literature, why these exist, what the difficulties may be and what can be done to make improvements for service users. Any research into service user and carer perspectives on diagnosis was also reviewed in order to inform the researcher's understanding of carrying out research from this point of view.

Searches were conducted using the electronic database Web of Knowledge (including Web of Science, BIOSIS Citation Index, BIOSIS Previews, Medline and Journal Citation Reports). The Cochrane Library database was also searched in order to identify any key systematic review papers. Leading journals in the field, namely the 'Journal of Affective Disorders' and 'Bipolar Disorders' were also systematically searched. Where appropriate, relevant research papers were also chosen from the reference sections of articles yielded by the database searches.

Web of Knowledge searches were refined by removing duplicates, only including articles published in or after 1980 until the current date, and selecting only those published in English. Searches were restricted to the subject areas of psychology, behavioural sciences and psychiatry. The searches carried out and the number of articles resulting from each (after the above criteria were applied) can be found in Appendix A.

The decision was made not to systematically search articles published prior to 1980 due to the study emphasis on the current issues in diagnosis in order to inform current services, as well as to simply refine the search. However, references prior to this were considered if they included ideas which were of high relevance (and therefore mentioned in later papers) or if there was a limited amount of research in a specific area.

The strategy applied was to begin using general search terms (e.g. 'bipolar' AND 'diagnosis' - plus possible variations of these words) and then to refine the searches using more specific terms. Initially, searches were carried out in the 'topic' field in Web of Knowledge, meaning that at least the abstract, title and keyword fields were searched. However, due to the sheer volume of research in the area, more specific searches were carried out by using the 'title' field and searching for review papers to gain an overview. Boolean operators were also used throughout

to refine searches. The search terms were selected to reflect the objectives of the study and were aimed at being as inclusive as possible.

The general search terms for bipolar disorder related experience/diagnosis were: *bipolar**, *manic-depression*, *atypical-depression*, *mani**, *hypomani**, *cyclothymi** and *mood-disorder*. (Additional synonyms and forms of terms were also be searched within these – e.g. *bipolar** would also identify bipolar disorder, bipolarity, bipolar spectrum, bipolar II, etc).

The general search terms for diagnosis were: *diagnos**, *misdiagnos**, *undiagnos**, *detect**, *undetected**, *identif**, *misidentif**, *unidentif**, *recogni**, *unrecogni**, *discover**, *undiscover**, *classif**.

Then more specific ideas were searched for within these articles e.g. *bipolar spectrum*, *delayed diagnosis*, *diagnostic validity*.

Search terms related to issues/debates were: *barrier**, *issue**, *difficult**, *controvers**, *argument**, *debat** *problem**.

Search terms regarding method of identification were: *screen**, *assessment**, *measure**, *questionnaire**.

Search terms relating to pre-diagnosis indicators were: *trait**, *clue**, *characteristic**, *risk**, *sign**, *feature**, *precursor**, *symptom**, *indicat**.

Search terms regarding service user views were: *service user**, *carer**, *patient**, *client**, *perspective**, *view**, *opinion**, *experience**.

Search terms relating to current services were: *primary care*, *general practi**, *family doctor**, *antidepressant**.

Once these searches were carried out, each abstract was read and selected as relevant if it met one of the criteria specified below.

Include papers:

- a) That review or report research into bipolar spectrum conditions
- b) That review or report research into debates and issues relating to diagnosing bipolar disorder (including use of antidepressants)
- c) That review or report research into current assessment and diagnostic processes (including screening tools)

- d) That review or report research into current healthcare services related to the diagnosis of bipolar disorder
- e) That consider service user/carer perspectives on diagnosis and services.

Where articles were very similar, e.g. review articles, those with the most citations were selected. For reviews on similar topics, those published most recently were prioritised. Articles were also selected on the basis of whether the full text was available.

1.2 BIPOLAR DISORDER

Historically described as manic-depression, what is now known as bipolar disorder can be a chronic and severe disorder characterised by the experience of periods of extreme elation and depressed mood that occur throughout a person's lifetime (Saunders & Goodwin, 2010). It is ranked by the World Health Organisation as one of the top 10 causes of disability (Saraceno, 2002) and has been connected with significant difficulties occupationally, high divorce rates, substance abuse and frequent suicide attempts (Kogan *et al.*, 2004; Kupfer *et al.*, 2002). It is also associated with a higher number of physical health problems than is found in the general population (Kilbourne *et al.*, 2009). However, bipolar disorder can also be linked to positive experiences such as ambitiousness, high productivity, many achievements and creativity (BPS, 2010; Jamison, 1996; Perkins, 1999).

1.2.1 Diagnostic criteria

According to the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV; American Psychiatric Association, 2000) bipolar disorder can be split into four types: Bipolar I, Bipolar II, Cyclothymia, and Bipolar Not Otherwise Specified (NOS). Bipolar I is characterised by the experience of one or more episodes of mania, which is often, but not always, accompanied by episodes of depressed mood. The more common bipolar II is characterised by at least one hypomanic episode, and at least one period of depression. In reality though, most patients will experience a number of both depressed and manic/hypomanic episodes throughout their lifetime (Saunders & Goodwin, 2010). Cyclothymia is described as a history of hypomanic episodes and periods of low mood which do not meet diagnostic criteria for depression. Bipolar NOS includes all other bipolar-type disorders which do not fit into the above three categories.

Mania is described in DSM-IV as an elevated, expansive or irritable mood which is markedly different from the individual's usual mood state, interferes significantly with occupational or social functioning and lasts at least a week (or less if hospitalisation is required). Mania includes at least three of the following symptoms: inflated sense of self-importance, decreased need for sleep, increased talkativeness, racing thoughts or ideas, distractibility, increased goal-directed activity and excessive engagement in often pleasurable but also highly risky behaviours. People may also experience grandiose delusions and other symptoms more typically associated with psychosis.

The criteria for hypomania are similar to those for mania but less extreme. A hypomanic episode lasts a minimum of four days, but does not involve the same level of significant impairment in functioning or hospitalisation. Those who have experienced mania or hypomania, however, also describe enjoyable and desirable aspects to the experience and during the episode can lack insight into the potentially serious risks or danger associated with their behaviour. For many people, hypomania in particular can be a positive experience linked to high work performance, productivity, enhanced self-confidence and an increased capacity to be sociable and gregarious (Seal *et al.*, 2008).

'...my manic depression is responsible for a great deal of the positive energy and creativity in my life. For a great deal of the time I am blessed with buckets of energy – more than most people. I love to work hard. My thoughts work like liquid crystal. I can see what things mean quickly and clearly. Ideas – generally good ideas – come to me with little or no effort.' (Perkins, 1999, p.137)

On the other hand, an episode of major depression is defined as a period of very low mood and loss of pleasure gained from previously enjoyed activities most of the day, nearly every day, for a period of at least two weeks. According to DSM-IV, it includes at least three of the following symptoms to meet diagnostic criteria; a change in appetite and/or weight, disturbed sleep, a decrease in physical activity, tiredness and loss of energy, feelings of worthlessness or guilt, poor concentration and suicidal thoughts. Current classification systems do not distinguish between the depression experienced in the context of bipolar disorder, and unipolar depression (depression with no evidence of elevated mood features during a person's lifetime). However, recent reviews suggest that there may be a number of differences between bipolar and unipolar depression (Bowden, 2005; Correa *et al.*, 2010; Nusslock & Frank, 2011). This will be discussed further in Section 1.7.2.1. The majority of people with bipolar disorder spend significantly more time depressed than manic (Post, 2003; Saunders & Goodwin, 2010) and, unlike the positive

aspects of mania sometimes reported, the experience of any kind of depression is generally described negatively, and evidence suggests that a bipolar depression can be particularly virulent and debilitating (Thase, 2006).

'It is true that I detest my depressions. I cannot make my thoughts work – it is like thinking through treacle. When my depression is at its worst I cannot make even the simplest choices about things like what to wear. I cannot follow conversations, I cannot drive, I cannot work, I am totally unrewarding to be with...' (Perkins, 1999, p.137)

People with bipolar disorder can also experience 'mixed episodes', where features of both depression and mania are present in the same time period, either alternating or occurring concurrently. Episodes like these are reported to be particularly difficult to cope with by those who experience them (BPS, 2010).

1.2.2 Prevalence

When DSM-IV diagnostic criteria are strictly adhered to, the lifetime prevalence of bipolar disorder is estimated at approximately one to two per cent (e.g. Ferrari *et al.*, 2010; Merikangas *et al.*, 2007; Pini *et al.*, 2005) with bipolar II being more prevalent than bipolar I (Kessler *et al.*, 2005). However, there is a growing body of evidence indicating that this is a considerable underestimate (e.g. Carta & Angst, 2005; Smith *et al.*, 2011), particularly with regards to bipolar II. Some researchers also describe a broader bipolar spectrum of clinically significant conditions which do not meet current diagnostic criteria (See Section 1.4.1). With these included, lifetime prevalence estimates would extend to five or six per cent (Judd and Akiskal, 2003; Merikangas *et al.*, 2011).

1.2.3 Course

The onset of bipolar disorder occurs under the age of 20 for approximately 60% of patients (Hirschfeld *et al.*, 2003; Merikangas *et al.*, 2007) with an overall mean age of onset being 22.2 years (Goodwin & Jamison, 2007). Complete remission is rarely reported (Ferrari *et al.*, 2010) and most longitudinal studies support the notion that bipolar disorder is a lifelong illness (Saunders & Goodwin, 2010). The most positive outcomes are usually a result of people learning to understand and effectively manage their symptoms (Sachs *et al.*, 2003).

1.2.4 Aetiology and treatment

Data from family, twin and adoption studies suggests that heritability accounts for a large proportion of the variability in the development of bipolar disorder (Goodwin & Jamison, 2007; Kieseppa *et al.*, 2004) and as such, the strong biological contribution to the disorder has implicated interventions of a pharmacological nature (Goodwin, 2009; Leahy, 2007). More recently the influence of environmental and psychosocial factors on the development of bipolar have been considered as important (Alloy *et al.*, 2005; BPS, 2010), in part due to researchers' recognition that biological and genetic processes are unable to account for differences in symptom expression and medication effectiveness. Accordingly, the stress-diathesis model, which suggests that life stress such as interpersonal conflicts, life events and unhelpful coping strategies can exacerbate symptoms, is considered to be an important part of the bipolar picture (Leahy, 2007). In addition, the influence of environment, upbringing, childhood events and cognitive style may all be factors in the development of bipolar disorder (Alloy *et al.*, 2005; BPS, 2010).

In terms of current treatment guidance, the focus is on pharmacological interventions, although psychosocial interventions are also mentioned (National Institute for Health and Clinical Excellence; NICE, 2006). The key recommendation for long-term treatment is prophylactic agents such as lithium or olanzapine (also described as mood-stabilizers) which are intended to prevent mood fluctuations. Anti-manic drugs (e.g. antipsychotics) can be used for acute periods of mania. Antidepressants are generally only considered appropriate for short-term use during acute depressive episodes, and only then alongside prophylactic medication. If antidepressants are being taken at the onset of mania, they should be discontinued as soon as possible. Due to drug interactions and lifestyle factors regular physical monitoring should be carried out.

However, most guidelines apply to bipolar I, and the evidence on treating bipolar II and bipolar NOS is limited (NICE, 2006). Despite comprehensive guidelines, there are no universally accepted approaches to treating bipolar disorder with medication, as effects can vary widely between patients (Treuer & Tohen, 2010). Due to the recognition that psychosocial variables also play an important part in the development and course of the disorder (Miller *et al.*, 2009), it is now generally acknowledged that psycho-education, social interventions and psychological therapy can be effective alongside or even instead of medication (Mansell *et al.*, 2007; Miklowitz *et al.*, 2008; Scott *et al.*, 2006; Smith *et al.*, 2010).

1.3 CONCEPT OF DIAGNOSIS

1.3.1 Overview

Mental health diagnostic decisions are made based on a collection of physiological, emotional, behavioural and cognitive symptoms experienced by an individual in a pattern which is consistent with a particular disorder. Diagnosing people in this way can organise and create understanding of a person's experiences, and can therefore be used as a basis for carrying out research or to make informed decisions about treatment based on clinical knowledge or research evidence (BPS, 2010). A diagnosis can also be useful to summarise to others what an individual is experiencing, and can be helpful in predicting the future course of a problem.

However, for diagnoses to be helpful to both professionals and service users, they need to be both reliable and valid, which is problematic for psychiatric diagnoses because, unlike physical health conditions, mental health symptoms are more difficult to objectively measure (Johnstone, 2006). The anti-psychiatry movement in particular has been highly critical of most psychiatric diagnoses, suggesting that they are vague, arbitrary and unscientific (Berlim *et al.*, 2003). Progress has been made in DSM-III and DSM-IV to establish the reliability of such diagnoses (Joyce, 2008), however for bipolar disorder the level of diagnostic agreement between clinicians remains variable (Zimmerman *et al.*, 2008).

In terms of validity, a diagnosis of bipolar disorder should indicate the appropriate treatment method and provide information about the symptoms and future prognosis. Whilst both of these are possible in broad terms, and a list of intervention options and possible future experiences may be generated, individual experiences of the most effective treatment and eventual long-term prognosis vary widely within those diagnosed with bipolar disorder (BPS, 2010).

Nevertheless, a diagnosis can be a starting point in terms of understanding what an individual is experiencing and narrowing down the most appropriate ways in which to help them, in a sense providing some order to the chaotic symptoms an individual may be struggling to cope with (Krueger & Piasecki, 2002). This seems particularly important for a mental health problem such as bipolar disorder which carries with it such significant risks of extreme distress, disability and physical harm to individuals (Nusslock & Frank, 2011).

1.3.2 Positive impact of diagnosis

Service users have described receiving a diagnosis as a helpful way of conceptualising, explaining and applying meaning to the difficulties they have had, both for themselves and as a way of concisely conveying their situation to others (BPS, 2011a). It can also legitimate a person's illness, enable them to gain support from services and connect with others diagnosed with the same condition, which can help with self-management and reduce feelings of isolation (Proudfoot *et al.*, 2009; Suto *et al.*, 2010).

Evidence-based treatment guidance is based on classification by diagnosis, and psychiatric diagnoses are necessary in order to access mental health services. Diagnostic labels are also understood in the legal system as well as being needed in order to claim disability benefits. A diagnosis can therefore provide service users with a route to support and treatment for their difficulties.

Acceptance of a bipolar diagnosis can contribute to favourable long term outcomes and improved quality of life (Clatworthy, 2007). If people feel ambivalent towards their diagnosis, then their attitudes to treatment tend to be unfavourable. Importantly, a combination of non-adherence to medication, lack of routine and difficult life events are linked to relapse for people with bipolar disorder (Goodwin & Jamison, 2007).

Various guidance and legislation is now in place in order to reduce stigma and prevent discrimination against people with physical and mental health disabilities in areas of employment and accessing services (e.g. Disability Discrimination Act, 2005; Equality Act, 2010). The recent government mental health strategy 'No Health without Mental Health' (Department of Health; DOH, 2011) also emphasizes the importance of inclusion and reducing discrimination for those with mental health problems. If awareness is raised, being diagnosed with a recognised condition can assist public understanding of unusual or distressed behaviour in the context of the mental health problem. The hope would be that this could result in people such as employers having a framework within which to support people through their difficulties. For people with bipolar disorder specifically, the recent media coverage of popular celebrities such as Stephen Fry discussing their experiences may also have served to destigmatise and promote public awareness of the condition (Chan & Sireling, 2010).

1.3.3 Negative impact of diagnosis

Alternatively, as reviewed by Sach and Rush (2003), bipolar disorder is considered to be a life-long condition, where complete cure is impossible and the most realistic treatment goals are sustained remission and an improved quality of life. Being diagnosed with this can therefore be disheartening for service users and feel like a 'life sentence', potentially increasing their sense of powerlessness and worthlessness (BPS, 2011). Having a bipolar diagnosis can also compromise an individual's sense of identity (Inder *et al.*, 2008).

Service users have also reported that lists of isolated symptoms as found in DSM-IV fall short of explaining the reality of actual patient experience (Joyce, 2008; Licinio, 2005). A psychiatric diagnosis does not explain the cause of a disorder, and indeed classification systems do not set out to do so (e.g. DSM-IV, 2000). Similar symptoms may actually have a very different underlying aetiology, which may render the diagnosis not particularly meaningful to those it applies to.

Being diagnosed with a psychiatric disorder that is considered to be severe and enduring can also be very stigmatising (Elgie & Morselli, 2007). As one service user reported: 'It is more mental illness per se than bipolar itself that is stigmatising. Public understanding of mental illness is very poor.' (BPS, 2010, p.33). One qualitative study found that people with bipolar disorder felt that much more stigma was associated with a mental versus a physical health condition, and more stigma was associated with bipolar disorder in particular, as opposed to unipolar depression (Michalak, 2006). The overall findings from this study suggested that people diagnosed with bipolar disorder experience considerable stigma which has a profound effect on their quality of life.

Despite recent strategies setting out to stop discrimination and improve the outlook for people with mental health problems (DOH, 2011), it seems that in reality a mental health diagnosis may still carry with it many negative associations. However, a diagnosis can also add meaning and understanding for service users, provide information about illness course and treatment options, and facilitate access to services.

1.4 ISSUES IN THE DIAGNOSIS OF BIPOLAR DISORDER

1.4.1 The bipolar spectrum

Diagnostic systems are often criticised for the over simplistic and seemingly arbitrary categorisation of symptoms or experiences, which, in reality, may lie on a continuum where there is overlap with normal human experience (Jones & Bentall, 2006). For example, most people experience variations in their moods, albeit some more extreme than others, but the point at which these fall within the realms of the diagnostic label of bipolar disorder seems difficult to quantify (BPS, 2010).

Indeed, with bipolar disorder, it is thought that there is broader bipolar spectrum of conditions that may fall below the threshold to meet a diagnosis of bipolar I or II but are characterised by extreme shifts in mood, and remain important clinically. Such conditions have been described as 'soft' bipolar (Smith, 2009) or bipolar III (Akiskal and Pinto, 1999). Current DSM-IV criteria are thought to be overly rigid in that they do not adequately consider these sub-threshold conditions, however there is indication that in DSM-V (due to be publicised in May 2013) the diagnostic criteria for hypomania will be slightly broader (see www.dsm5.org; American Psychiatric Association, 2012; also Zimmerman *et al.*, 2009). Along this line of reasoning, some researchers suggest that all affective disorders exist on the same dimension, with major depression with no bipolar features at one end and bipolar I with psychotic mania at the other (Angst *et al.*, 2010; Merikangas *et al.*, 2007). However, others suggest that there are qualitative differences between those with more 'straightforward' depression and those with depression and evidence of sub-threshold manic or hypomanic symptoms, the latter being more similar to those with bipolar disorder on a number of clinical validators (Nusslock & Frank, 2011) and significantly more likely to convert to full syndrome bipolar disorder over time (Zimmerman *et al.*, 2009). It also seems that the various sub-threshold forms of bipolar disorder are associated with considerable impairment exceeding that experienced by those with no evidence of bipolarity (Nusslock & Frank, 2011). Current diagnostic algorithms may mean that clinicians are unaware of, or unlikely to assess, this range of significant difficulties in their patients.

1.4.2 Over-diagnosis

One of the difficulties with the notion of classifying conditions such as depression with sub-syndromal hypomanic features as part of the bipolar spectrum is the risk that these bipolar type-

disorders may become over-diagnosed. There is a literature suggesting that there are some circumstances in which this could be the case (e.g. Zimmerman *et al.*, 2008) but the argument tends to be that this is due to features of other disorders being attributed to bipolar disorder, such as borderline personality disorder (Ruggero *et al.*, 2010). Those advocating the recognition of a wider bipolar spectrum call for more in-depth understanding and assessment of bipolarity (Nusslock & Frank, 2011) which would also serve to reduce any risk of inappropriate diagnosis in certain populations.

Additional debates surround the recent trend of diagnosing bipolar disorder in children and young people, particularly in the USA. Moreno and colleagues (2007) found a rapid increase in the diagnosis of paediatric bipolar disorder in clinic-based settings between 1994 and 2003. However, others believe that this increase may reflect previous bipolar under-diagnosis and misdiagnosis with conditions such as Attention Deficit Hyperactivity Disorder (ADHD). In what is reported to be the first controlled research on this topic, Chilakamarri and colleagues (2011) found that bipolar disorder was still under-diagnosed in children, and that ADHD was much more likely to be over-diagnosed. The current study focuses on adult experience of being diagnosed with bipolar disorder, therefore a detailed analysis of the important issues regarding the diagnosis of paediatric bipolar disorder is beyond the scope of this review.

1.4.3 Under-diagnosis

Current research trends report that under-diagnosis and lack of recognition of bipolar disorders that are already classified in DSM-IV are the most problematic issues for adults. Large survey and outcome studies suggest that people often have to wait a long time between first experiencing symptoms, seeking help, and eventually being diagnosed with bipolar disorder, and they may be misdiagnosed with a variety of other disorders during the interim. The following sections will describe these issues in more detail.

1.4.3.1 Delayed diagnosis

Berk and colleagues (2007) administered 218 questionnaires to participants enrolled in the Bipolar Comprehensive Outcomes Study, which asked about their experience of symptoms, help-seeking and diagnosis. They discovered that people experiencing bipolar disorder waited a mean of twelve years between first experiencing serious depressed mood symptoms and being

accurately diagnosed. The wait between experiencing symptoms of mania and diagnosis was nine years, with six years wait between first seeking medical help for these symptoms and receiving a diagnosis of bipolar disorder. The study also revealed that the earlier the onset of symptoms the greater the diagnostic delay.

Similarly, earlier clinic based studies interviewing 48 and 85 patients respectively about their experience of affective symptoms reported delays of between six and ten years before bipolar I or II were correctly diagnosed and appropriate treatment was offered (Ghaemi *et al.*, 1999; Ghaemi *et al.*, 2000). The latter study also compared the length of time between first help-seeking and diagnosis for those with unipolar and different types of bipolar depression. This revealed that those with depression waited on average 3.3 years before being diagnosed, those with bipolar I waited almost 6 years, but those with bipolar II could wait almost 12 years, suggesting that identifying hypomania in patients is particularly problematic.

A Depression and Bipolar Support Alliance (DBSA; previously Depression and Manic-Depression Association) postal survey of 600 of its members in 2000 found that 35% waited more than 10 years between seeking help for bipolar related symptoms and being diagnosed with bipolar disorder (Hirschfeld *et al.*, 2003). However, this was a slight improvement compared to a similar survey carried out by the same organisation in 1992, where 41% of 500 participants reported over 10 years delay (Lish *et al.*, 1994). Another postal survey study carried out across Europe and involving 1041 participants with bipolar disorder found that people tended to wait a mean of 5.7 years between symptom onset and correct diagnosis (Morselli & Elgie, 2003).

The difficulty with gaining a complete picture of the length of actual diagnostic delay depends on the way in which the questions are asked and what is judged to be the starting point for delay. The study by Berk and colleagues (2007) included comprehensive questions relating to first onset of any symptoms, first mood swings, first depressive symptoms, first depressive episode, first manic symptoms, first manic episode, first help seeking and finally time of diagnosis in order to paint a more detailed picture. However, other studies have asked less thorough questions.

It is also important to note that these studies all asked participants to retrospectively recall their symptom histories (although the research by Ghaemi and colleagues also consulted patient records and family members to corroborate self-reports) which is problematic with regards to the accuracy of human memory. Another difficulty with bipolar participants retrospectively judging

early depressive symptoms as being the first signs of illness is that these symptoms could also occur in somebody who never goes on to develop bipolar disorder. It may therefore be more accurate to consider diagnostic delay in bipolar disorder from the point of patients' first experiences of hypomanic, manic or mixed affective symptoms. In terms of a service user perspective, it may be that the most appropriate reflection of diagnostic delay is the length of time between them first seeking help for what they consider to be bipolar symptoms, and them then being diagnosed with bipolar disorder.

However, regardless of these methodological and practical limitations, from the studies reported here, it seems that delays in being appropriately diagnosed affect a large proportion of people with bipolar disorder, who can wait an average of between 5.7 to 12 years of experiencing symptoms before receiving a bipolar diagnosis.

1.4.3.2 Misdiagnosis

A major contributory factor to a diagnostic delay is the issue that many people with bipolar disorder are first misdiagnosed with one or a number of different conditions. In the DBSA survey (Hirschfeld *et al.*, 2003) 69% of respondents reported being misdiagnosed with a mean of 3.5 different conditions before eventually being diagnosed with bipolar I or II. These misdiagnoses included anxiety disorders, schizophrenia, borderline personality disorder, alcohol/substance misuse and schizoaffective disorder. However the most frequent misdiagnosis was unipolar depression, with 60% of those misdiagnosed being previously thought to have this condition. Misdiagnosed participants had also consulted a mean of four doctors before being correctly diagnosed with bipolar disorder. This study also found that women were significantly more likely to be misdiagnosed than men, and that women were more likely than men to be misdiagnosed with depression, whereas men were more frequently misdiagnosed with schizophrenia than women. Berk and colleagues (2007) also reported similar findings; when initially seeking treatment, 56% of the participants in the study had previously received a diagnosis other than their current diagnosis of bipolar disorder, most commonly major depressive disorder.

In the study reported by Ghaemi and colleagues (1999), 40% of participants with bipolar I disorder had previously been misdiagnosed with unipolar depression. Their follow-up study indicated that 37% of those with bipolar I, II or NOS were still diagnosed as having unipolar

depression despite having already sought help for manic or hypomanic symptoms (Ghaemi *et al.*, 2000).

Hirschfeld and colleagues (2005) screened 180 adult patients being treated for depression in a family medicine clinic and found that 21.3% showed significant signs of having bipolar disorder. These findings were supported by also carrying out a more detailed clinical interview on a subsection of those who screened both positively and negatively for bipolar disorder.

Das and colleagues (2005) screened a sample of 1157 adult primary care patients seeking a face-to-face consultation with a physician and found that 9.8% screened positively for bipolar disorder. Whilst 88.4% of those who screened positively had previously been given a psychiatric diagnosis, only 8.4% indicated they had ever been diagnosed with manic depression or bipolar disorder, despite 72.3% specifically seeking help for manic or hypomanic symptoms.

In the first UK based study investigating rates of unrecognised bipolar disorder in primary care (Smith *et al.*, 2011), 3117 patients with a working diagnosis of unipolar depression from 11 GP practices in South Wales were invited to take part by practice managers. Based on a face-to-face diagnostic interview with a selection of respondents, a conservative estimate of previously unrecognised bipolar disorder was approximately 10%, which was intermediate between a more conservative estimate of 3.3% and a much less conservative estimate of 21.6%. Bipolar II and bipolar NOS were the most common diagnoses, but there was some evidence of bipolar I also not being identified.

These studies all indicate that bipolar disorder is significantly under-recognised and is most frequently misdiagnosed as unipolar depression. In primary care settings in both the USA and the UK, over 20% of people being treated for major depressive disorder may actually have current DSM-IV diagnosable bipolar disorder (Hirschfeld *et al.*, 2005; Smith *et al.*, 2011). However, if the broader bipolar spectrum is considered, there may be an even greater number of people who are not being appropriately diagnosed.

1.5 IMPLICATIONS OF DIAGNOSTIC INACCURACY

Evidence suggests that the delayed diagnosis, under-diagnosis and misdiagnosis of bipolar disorder occur frequently and this is problematic for a number of reasons. Major issues with misdiagnosis include the risk of people being treated inappropriately, particularly with unhelpful

medication. For those who remain undiagnosed with bipolar disorder for significant amounts of time, a worse long-term prognosis and reduced overall quality of life is implicated. There are also increased healthcare costs associated with unidentified and untreated bipolar disorder. The following sections will consider these implications.

1.5.1 Inappropriate medication

A major difficulty with the misdiagnosis of bipolar disorder as unipolar depression is that service users may be prescribed inappropriate medication. Individuals diagnosed with depression in primary care are likely to be prescribed antidepressant medication as recommended by National Institute for Health and Clinical Excellence (NICE) guidance (2009). Indeed, the number of antidepressant prescriptions in the UK has increased by 28% from 2007-08 to 2010-11 (Batty, 2011) suggesting that their use is becoming increasingly commonplace.

However, antidepressants can be unhelpful (Rybakowski, 2011; Sachs *et al.*, 2007) or even harmful for people with a bipolar depression (Goldberg & Truman, 2003) as they can reportedly induce a mood switch to mania as well as rapid cycling mood episodes (Altshuler *et al.*, 1995; Ghaemi *et al.*, 2000; Goodwin, 2009; Peet *et al.*, 1994). They have also been linked with self-harming and suicidal behaviour (McElroy *et al.*, 2006; Smith & Walters, 2007). Recent reviews of the risks associated with antidepressant use for people with bipolar disorder have concluded that the adverse effects are not fully established (Grunze, 2008; Tundo *et al.*, 2011) and methodological criticisms can be levelled at many studies attempting to draw these links. However, despite this, it is noted that there is little doubt that antidepressants cause mood instability (El-Mallakh *et al.*, 2008) which may give rise to additional worries such as increased suicidality, and that there is likely to be a subgroup of patients at greater risk of these adverse effects (Grunze, 2008). It is also likely that broader spectrum antidepressants such as tricyclics present a greater risk of mood-switching than more selective alternatives such as selective serotonin reuptake inhibitors (SSRIs) (Gijsman *et al.*, 2004; Koszewska & Rybakowski, 2009).

Accordingly, NICE (2006) recommends that, for bipolar disorder, anti-depressants should be prescribed with caution and not without additional mood stabilising medication, which is problematic if possible bipolar disorder is frequently being diagnosed as unipolar depression where antidepressant monotherapy is recommended (NICE, 2009). Tundo and colleagues (2011) highlight the need for detailed assessment and personalised interventions for people with

bipolar disorder to ensure that any potential risks associated with anti-depressant use in this population are reduced.

1.5.2 Poor prognosis

Research has shown that the early identification and treatment of bipolar disorder leads to better outcomes and long-term prognosis, more adaptive functioning and less social and occupational interference (Thomas, 2004). In the BDSA survey (Hirschfeld *et al.*, 2003), service users reported that after being correctly diagnosed and receiving treatment, interpersonal conflicts, marital difficulties, financial problems and alcohol and substance abuse all dropped significantly. Early intervention is recommended to improve outcomes, and this is the case for both pharmacological and more psychosocial interventions such as CBT and psycho-education (Goodwin, 2009; Scott *et al.*, 2006; Smith *et al.*, 2010).

However, unrecognised and untreated bipolar disorder can have a devastating and potentially life-threatening impact on affected individuals, as people are at greater risk of alcohol and substance abuse, more extreme risk-taking behaviours and suicide (Lewis & Hoofnagle, 2005). Gazelle and colleagues (2005) found that the greater the length of time between illness onset and diagnosis, the worse the impact on participants' physical and psychological quality of life. In terms of illness course, greater delays in diagnosis and lack of treatment are associated with a higher lifetime episode frequency and more severe episodes (Gutierrez-Rojas *et al.*, 2010; Post & Leverich, 2006).

Acceptance of diagnosis (Clatworthy *et al.*, 2007), as well as an awareness of triggers and warning signs (Proudfoot *et al.*, 2009), are thought by service users to contribute to maintaining wellness and helping them to have a degree of control over their difficulties. Service users are likely to be less accepting of their diagnosis when they have previously experienced misdiagnosis and uncertainty from professionals, leading to mistrust of services and doubt about what is best for them (Inder *et al.*, 2010) which in turn can mean that they may face less favourable long term outcomes. It therefore seems that both delayed diagnosis and misdiagnosed bipolar disorder can have detrimental effects on the course of illness and quality of life of service users.

1.5.3 Economic costs

Bipolar disorder is a complex condition with high associated healthcare costs. In the UK alone the annual cost of bipolar disorder to the NHS has been estimated at £342 million (Young *et al.*, 2011). However, the indirect costs to society of unidentified bipolar disorder far exceed those for both recognised bipolar disorder and unipolar depression (McCombs *et al.*, 2007). Diagnostic delays also appear to be related to increased healthcare costs even after people are eventually diagnosed (Stang, 2006). The picture is further complicated when those with undiagnosed bipolar spectrum conditions are considered, as bipolar depression is associated with more significant costs than unipolar depression (Kessler *et al.*, 2007). In particular, treating bipolar depression inappropriately with antidepressant medication can have serious consequences for individuals with associated elevated healthcare costs. An example of this could be paying for hospitalisation which may not have occurred with appropriate assessment, treatment and monitoring (Amey, 2010; Birnbaum *et al.*, 2003). This highlights the fact that an additional reason for the timely recognition of bipolar disorder is to minimise possible health care costs (McCombs *et al.*, 2007).

With the considerable problems that unrecognised bipolar disorder presents to both individuals and healthcare services alike, there is a rationale for awareness of bipolar disorder to be raised and diagnostic accuracy to be improved. However, there are a number of reasons why identifying bipolar disorder is challenging, and these exist from both a service user and healthcare provider perspective.

1.6 WHY DIFFICULTIES IN THE DIAGNOSTIC PROCESS EXIST

1.6.1 Service user barriers

Despite mania and hypomania being the distinguishing characteristics of bipolar disorder, depression is usually the dominant mood polarity when considering both length of time affected and number of episodes. This is the case for both bipolar I (Judd *et al.*, 2002) and bipolar II (Judd *et al.*, 2003). Service users are therefore much more likely to approach their GP for help with the experience of depression (Akiskal, 1996; Ghaemi, *et al.*, 2002) due to both its frequency and its distressing, disabling impact on wellbeing and everyday functioning (Mitchell & Malhi, 2004).

Alternatively, when having an episode of hypomania, people may experience increased productivity and find themselves more sociable, productive and creative (BPS, 2010) so it is unlikely that people would choose to seek specific help to alter these seemingly desirable experiences. However, during episodes, service users can also lack insight into the downsides of hypomanic and manic experiences, such as irritability, risk-taking behaviour and a lack of appreciation of consequences (Angst & Cassano, 2005) which in mania may result in serious harm. Manic and hypomanic experiences can therefore be significantly underreported (Lewis, 2004) both due to them being relatively rare in the course of the illness, and there being less incentive for service users to seek help for these symptoms.

Stigma can also be a factor in whether people choose to seek help for mental health problems (Schomerus & Angermeyer, 2008) as it can create challenges for those affected and the people close to them. Over half of those with bipolar disorder reported feeling embarrassed or ashamed at the time that they were first diagnosed (Lewis & Hoofnagle, 2005). In a European survey study 50% of over 1000 bipolar diagnosed respondents reported stigmatisation as an issue, and almost a third felt rejected by their social environment (Morselli & Elgie, 2003). Participants also struggled to find employment despite high academic achievements. In the DBSA surveys, participants reported that a diagnosis of bipolar disorder had a more negative impact on employment in 2000 than it did in 1992, with more people indicating that they were treated differently from other employees in the most recent survey (Hirschfield *et al.*, 2003; Lish *et al.*, 1994). The fear of stigma and feelings of shame may therefore also result in people's reluctance to seek help for their difficulties (Lewis, 2005), contributing further to the difficulty of a bipolar presentation being identified.

1.6.2 Service provider barriers

1.6.2.1 Current focus in primary care

In primary care settings, the identification and management of major depression has improved considerably in recent years (Hirschfeld *et al.*, 2005). It is noted that the increase in scientific interest in unipolar depression may have been influenced by a wide variety of antidepressants becoming available (Ghaemi *et al.*, 2002). However, this has resulted in overlooking the subset of patients presenting as depressed who may have bipolar disorder (Hirschfeld *et al.*, 2005), especially as this is less pharmacologically straightforward to treat.

For the reasons outlined in Section 1.6.1, when patients seek help in primary care, consultations are likely to be depression-focussed in line with their needs at the time. Understandably, it is therefore not routine practice to assess all depressed patients for previous manic symptoms as this may not seem relevant at the time. Additionally, as GPs have a limited period of time with each patient, when approached by a large number of service users with low mood, assessing each one for possible bipolar disorder may just not seem appropriate or feasible (Smith *et al.*, 2010b).

However, as Muzina and colleagues (2007) highlight, depression is not just unipolar. DSM-IV major depressive disorder is a diagnosis of exclusion, meaning that a diagnosis should only be given if all other possible explanations for the low mood, including general medical conditions, grief, and other mental health conditions, perhaps most importantly bipolar disorder, have been ruled out. Yet practitioners report that systematically screening for bipolarity is the exception rather than the norm, even in those with a history of mood instability (Angst *et al.*, 2010; Brickman *et al.*, 2002).

1.6.2.2 Inadequate knowledge or training

In a survey of public understanding and knowledge of mental health conditions, 48% of people had not heard of bipolar disorder or manic depression (Lewis, 2005). Indeed, society's awareness and acceptance of mental health problems is limited. As the recent Mental Health Strategy 'No Health Without Mental Health' outlined (DOH, 2011), British society's awareness of mental health problems needs to be improved to reduce stigma and discrimination and to improve the quality of life for those affected. It also suggests that mental health should be treated on a par with physical health.

However, there is also a view that not just the general public, but healthcare professionals too, have a limited knowledge of bipolar disorder and how to assess, identify, and appropriately treat it. Inder and colleagues (2010) report that some service users described professionals only tentatively diagnosing them with a variety of things, offering little explanation, and yet still prescribing them various medications regardless of this. Elgie and Morselli (2007) suggest that many GPs have comparatively very little training in or experience of mental health issues, with the majority of their knowledge being based in the physical health realm, which can limit their ability to identify conditions such as bipolar disorder.

A survey study investigating family physicians' experience and confidence in diagnosing bipolar disorder was carried out in Canada (Balachandra *et al.*, 2005). Whilst the majority of 147 respondents reported that they were 'somewhat comfortable' diagnosing bipolar disorder, 42% rated their undergraduate and postgraduate training on bipolar disorder as poor, and 65% indicated that they would like more education on diagnosis, suggesting that there would certainly be room for improvement. Similarly, Chengappa and Williams (2005) surveyed 500 psychiatrists about their views on barriers to the effective management of bipolar disorder. Following this, Lewis (2005) compared the unmet needs identified by clinician respondents in this survey with unmet needs highlighted by service users themselves in a DBSA survey (Hirschfeld *et al.*, 2003) and found considerable differences of opinion. Another study investigated psychiatrists' use of clinical guidelines in clinical decision-making, and found that evidence-based guidelines for bipolar disorder were not widely implemented (Perlis, 2007). This suggests that general clinician understanding of bipolar disorder may have limitations.

1.6.2.3 Flaws in the assessment process

If the assessment of bipolar disorder is carried out, further barriers to identification may lie within this process. One key issue is the failure to include the views of relatives and carers (Ghaemi *et al.*, 2002), which could potentially address the issue of service users lacking insight into the severity of their symptoms. For example, a study assessing prodromal and residual symptoms in 74 service users diagnosed with bipolar I found that relatives were over twice as likely to report behavioural symptoms of mania than the patients were themselves (Keitner *et al.*, 1996).

Bruchmuller and Meyer (2009) concluded from their study that diagnostic decision making may also be flawed. When clinicians were asked to decide from case vignettes whether a diagnosis of bipolar disorder was appropriate, they found that if a plausible explanation was offered for the hypomanic symptoms, such as having just fallen in love, clinicians would be less likely to suggest a bipolar diagnosis despite all DSM-IV criteria being present. In a follow-up study, Wolkenstein and colleagues (2011) noted that clinicians often made heuristic biases when diagnosing bipolar disorder and tended to follow an additive rule rather than diagnosing on the basis of pre-defined DSM-IV criteria. Zimmerman and Mattia (1999) also reported that clinical practice assessments tend to be unstructured and unsystematic, leading to a greater rate of undetected conditions.

Another difficulty with the accurate and timely diagnosis of bipolar disorder may be that professionals simply do not ask the most helpful or relevant questions in a way that participants understand. As reported by Inder and colleagues (2010) one patient explained: 'I didn't know they were manic episodes. So when he [the psychiatrist] said 'have you ever been high' I thought to myself 'no', but then it wasn't really explained to me what that was.' (p.160.) Difficulties like this may be even more problematic for those who do not experience typical mania or hypomania yet have symptoms consistent with the broader bipolar spectrum.

It seems that there are a number of explanations from both a service user and service provider perspective as to why bipolar disorder goes unrecognised and undiagnosed. The following section will consider ways in which these difficulties could be overcome.

1.7 IMPROVING THE IDENTIFICATION OF BIPOLAR DISORDER

1.7.1 Screening and assessment tools

One barrier to the accurate assessment of bipolar disorder is that research that focuses specifically on methods of diagnosis is relatively sparse compared other conditions such as depression (Miller *et al.*, 2009). There are in-depth structured interviews which represent the most reliable and valid approach to diagnosing bipolar disorder when carried out by a trained professional (Akiskal, 2002). The two most common of these are the Structured Clinical Interview for *DSM-IV* (SCID; First *et al.*, 1997) and the Schedule for Affective Disorders and Schizophrenia (SADS; Endicott & Spitzer, 1978). However, whilst these are considered to be accurate in the diagnosis of bipolar I, they are more limited when it comes to the diagnosis of bipolar II (Simpson *et al.*, 2002). Additionally, these interviews are lengthy and involve considerable time to administer, rendering them unsuitable to be used in primary care practice. Yet as primary care is the first point of access to further services, several screening and self-assessment tools have been developed to help identify people who may need further assessment (Miller *et al.*, 2009).

However, of the various screening tools that have been devised for bipolar disorder, few have been applied to routine clinical practice and many are still thought to be too long or too complicated for primary care use, whilst others do not have robust and comparable psychometric characteristics (Allen and Smith, 2008; Baldassano, 2005; Miller *et al.*, 2009). A brief review of these follows.

The General Behaviour Inventory (GBI; Depue *et al.*, 1981) has been shown to be both sensitive and specific as a diagnostic screening tool. However, there are numerous versions of this instrument, meaning that its psychometric properties are difficult to generalise. With 73 items, it is also fairly lengthy. The Hypomanic Personality Scale (HPS; Eckblad & Chapman, 1986) is also fairly long, and has not shown consistent utility across clinical and non-clinical samples (Kwapil *et al.*, 2000). Two of the most recent screening questionnaires, the Mood Disorder Questionnaire (MDQ; Hirschfeld *et al.*, 2000), and the Bipolar Spectrum Disorder Scale (BSDS; Ghaemi *et al.*, 2005), have been found to successfully rule out bipolarity, but are not as sensitive when it comes to ruling it in (Phelps & Ghaemi, 2006; Zimmerman *et al.*, 2009; Zimmerman *et al.*, 2010). The MDQ in particular seems to ask questions in a manner which captures common experiences in community samples, resulting in 90% of students responding positively on some items in one study (Miller *et al.*, 2009).

The Hypomanic Checklist (HCL-32; Angst *et al.*, 2005) was developed to help identify hypomanic symptoms in people with depression, and has been successful in identifying both bipolar I and II in different settings (Meyer *et al.*, 2007), although Smith and colleagues (2011) also found that this tool yielded many false positives. With 32 items, it could also be considered too lengthy to qualify as a routine primary care screen. One study successfully reduced the HCL-32 to a 16-item version, without any notable changes to its sensitivity and specificity (Forty *et al.*, 2010). This 16-item version may be a useful tool in time-limited clinical settings, however it requires further validation.

There is some debate over whether available screening tools, although flawed, may be more helpful in primary care settings than no screening at all. Using a decision-analysis model, Menzin and colleagues (2009) compared the potential costs of screening for bipolar disorder in primary care using the MDQ as opposed to no screening over a 5-year period. They considered that a one-time screening programme in primary care could significantly reduce healthcare costs. One study has also linked high MDQ scores to increased impairment as well as suicidal ideation among people presenting in primary care (Das *et al.*, 2005). Yet Zimmerman and colleagues (2009) recently argued against the usefulness of the MDQ in routine clinical practice, suggesting that if a tool is used, the MDQ, although the most widely studied, may not be the most appropriate.

Gaynes and colleagues (2010) recently assessed the feasibility and validity of a new 27-item screening for mood and anxiety disorders known as the M-3 Checklist. They found that all

modules (including that for bipolar) had equal diagnostic accuracy to single disorder screens, and suggested that the M-3 could help to facilitate appropriate diagnoses in primary care. Currently, though, it seems that there is little agreement on what constitutes an adequate brief assessment questionnaire, resulting in there being no routinely used screen for bipolar disorder, particularly in primary care practice. Further research into a brief, sensitive screening tool to identify the bipolar spectrum in patients presenting in primary care with depression is therefore warranted.

1.7.2 Investigating additional indicators

If there is little agreement on what constitutes an appropriate screening tool, it is possible that those developed are not following the most appropriate lines of enquiry. A growing body of research and clinical experience suggests that there may be indicators and risk factors for bipolar disorder which are not part of current diagnostic criteria or screening tools.

1.7.2.1 Bipolar depression

Research has indicated that there are qualitative differences in the way bipolar depression and unipolar depression is experienced, despite the fact that in DSM-IV, both types of depression have exactly the same criteria. For example, features of atypical depression, such as hypersomnia, increased appetite, motor slowing, leaden paralysis and mood lability are thought to be more consistent with a bipolar depression (Akiskal & Benazzi, 2005; Bowden, 2005; Mitchell *et al.*, 2008; Swann *et al.*, 2005). Additionally, the presence of psychosis and more frequent depressive episodes of shorter duration are relevant (Forty *et al.*, 2008; Mitchell *et al.*, 2010), as are agitation, irritability, suicidal ideation, greater functional impairment and comorbid anxiety symptoms (Muzina *et al.*, 2007; Schaffer *et al.*, 2010). Increased rates of alcohol consumption, substance abuse and tobacco use have also been found in bipolar compared with unipolar depression (Angst *et al.*, 2003). A cyclothymic temperament predicts bipolar disorder in recurrently depressed patients (Mechri *et al.*, 2011), and mixed depression is also a validator of bipolarity (Benazzi & Akiskal, 2008). As discussed in Section 1.5.1, resistance or an adverse reaction to traditional antidepressant medication is also indicative of bipolar disorder (Muzina *et al.*, 2007).

1.7.2.2 Age of onset and family history

A particularly significant indicator of bipolar risk status is thought to be an early age of onset (under 21 years of age) of first major depressive episode (Akiskal *et al.*, 2000; Angst *et al.*, 2010; Schaffer *et al.*, 2010). Benazzi and Akiskal (2008) reported that the likelihood of an individual with major depression converting to bipolar disorder was three times higher if the depression had been early onset. Finally, family history of mood disturbance in general is an important risk factor (Angst *et al.*, 2003; Bowden, 2005) as well as family history of bipolar disorder specifically (Goodwin & Jamison, 2007; Muzina *et al.*, 2007), particularly in first degree relatives (Swann *et al.*, 2005). In fact, taking a family history of mood disorders is arguably more helpful for identifying bipolar disorder than any of the current diagnostic criteria (Vieta & Phillips, 2007). Professionals could therefore look for symptoms more consistent with atypical or bipolar depression, early age of onset, and family history of mood disorders when patients present with low mood in order to identify possible bipolar disorder.

1.7.2.3 Pre-diagnosis factors

There are a number of other reported indicators of, or precursors to, the development of bipolar disorder in the research literature, which can be environmental, psychological and behavioural, as well as associations with other physical and mental health conditions. Many studies have found that adverse or stressful life events tend to precede first onset of both depressed and manic/hypomanic mood episodes in bipolar individuals (Alloy *et al.*, 2005), although lifetime traumatic events (such as physical or sexual abuse in childhood) are also connected to the later development of bipolar disorder (Leverich *et al.*, 2002). Various psychological factors such as cognitive style or personality features have been connected to bipolar disorder. Goal striving, perfectionism, self-criticism and autonomy are thought to characterise cognitions of people with bipolar (Alloy *et al.*, 2005). Mansell and colleagues (2007) also report a connection with increased sensitivity of the 'behavioural activation system', which controls reward-seeking behaviour. One particular trait frequently linked to bipolar disorder both anecdotally and in research is that of creativity (Murray & Johnson, 2010; Runco, 2004). Lifetime behaviours, such as creative achievements, learning various languages, wearing flamboyant clothes, multiple relationships and professional instability have also been linked to bipolar disorder and may serve to identify potential bipolarity in those with depression (Akiskal, 2005).

Co-morbidities with other physical conditions occur frequently for people with bipolar disorder. Physical complaints which are more common than in the general population include migraines (McIntyre *et al.*, 2006) high blood pressure (Johannessen *et al.*, 2006), diabetes (Cassidy *et al.*, 1999), obesity, thyroid problems and vascular system complaints (Saunders and Goodwin, 2010). However, in terms of being indicators for bipolar disorder, for many physical complaints it is not known whether they precede its onset or may occur as a result of either bipolar implicated behaviour or medications (Krishnan, 2005).

With the exception of childhood trauma, and other non-behaviour dependant life events, for many of these potential indicators, it is difficult to establish whether they occurred before the onset of bipolar disorder or whether they were only evident after symptoms had developed, especially as the vast majority of studies into such issues utilise a retrospective design.

Some researchers have attempted to investigate features of a bipolar prodrome to improve the early identification of bipolar disorder. Skjelstad and colleagues (2010) reviewed eight studies providing information about a possible prodrome. Common experiences were the presence of irritability, aggressiveness, anxiety, hyperactivity, disturbed sleep, mixed mood symptoms and mood swings. However, none of these signs were specific or easily generalised apart from an overall dysregulation of energy and mood. The average duration of the prodrome was also difficult to specify. The authors conclude that more research into bipolar indicators is necessary, and that there is a particular need for qualitative research to gain more in-depth information from the perspective of service users (Skjelstad *et al.*, 2010).

1.7.3 Improving practice

Many authors highlight the need for primary care clinicians to be alert to the warning signs and risk factors for bipolar disorder in those presenting with depression, particularly with regards to age of onset, family history and differentiators between bipolar and unipolar depression (Berk *et al.*, 2005; Das *et al.*, 2005; Mitchell *et al.*, 2010; Muzina *et al.*, 2007; Piterman *et al.*, 2010; Swann *et al.*, 2005). Yet it seems that this message has not filtered through to routine practice in the UK (Smith *et al.*, 2011), suggesting that more education and training about bipolar disorder is warranted.

In France, government initiatives have recently put in place a series of bipolar management education programmes for primary care staff (Hantouche *et al.*, 2009). Rouillon and colleagues

(2011) carried out a survey comparing the practice of 45 GPs who had been trained using the programme 'Bipolact', with 50 who had not. They discovered that trained physicians showed a significant improvement in their ability to identify both bipolar I and bipolar II, whereas this improvement was not evident in those who had not yet been trained. The 'Bipolact' programme involved only two 1.5 hour sessions delivered by an experienced psychiatrist to a group of clinicians, suggesting that programmes such as these could be an effective way of improving the identification of bipolar disorder.

Whilst it may be unrealistic to expect primary care professionals to thoroughly assess bipolar disorder in every patient who presents with depression, a few carefully asked questions may give an indication as to whether that person should be referred for a more in-depth mental health assessment. According to Lewis and Hoofnagle (2005), professionals should ask questions which are targeted, e.g. about hours of sleep or recent activities, rather than more general questions about how people are feeling. Muzina and colleagues (2007) suggest that when patients present with depression, clinicians ask specifically about family history and past manic or hypomanic symptoms, as well as gaining additional information from the patient's family.

As professionals and service users may differ in their views about where the greatest areas of unmet need lie in the management of bipolar disorder (Lewis, 2005), a useful approach may also be to consider service user views on how to improve the diagnosis of bipolar disorder.

1.8 SERVICE USER AND CARER PERSPECTIVES

1.8.1 Overview

Research into bipolar disorder is often dominated by randomised controlled trials and funded by pharmaceutical companies, and whilst the majority of US and UK based research highlights the delayed and incorrect diagnosis of bipolar disorder, it could be assumed that this research agenda is in the best interests of those who fund the research (BPS, 2010). More people diagnosed with a mental health disorder which is most commonly treated with a combination of psychoactive medication means a greater income for pharmaceutical companies. Bearing this in mind, it seems important to also consider the views of service users themselves on the diagnosis of bipolar disorder and the services they have received as the people who are directly affected. However, the experience of individual service users is undervalued and rarely

considered in the published literature, and the views of carers are even more frequently neglected (Elgie & Morselli, 2007). Specifically, despite the importance placed on individuals accepting their bipolar diagnosis in terms of improved outcomes and quality of life, there is little research into service users' opinions on the process of diagnosis and its impact on them (Inder *et al.*, 2010).

After considering the difficulties associated with diagnosing bipolar disorder, the reasons that these difficulties exist and the possible ways in which they could be overcome, this section sets out to consider what service users think about these issues by reviewing what available evidence there is from their perspective. Of the studies which do take into account service user and carer opinion, some have already been mentioned where relevant in previous sections of this review. This section will therefore provide an overview of these studies and consider how they are relevant to the present study.

1.8.2 First person narratives

Licinio (2005) published an account written anonymously by a mental health professional with bipolar disorder. Whilst the article discusses views on treatment history and the experience of bipolar disorder generally, the author makes a few comments on the topic of diagnosis. Whilst she was diagnosed at the age of 18, she makes it clear that, in her view, the illness began years earlier. She also reports feeling angry towards family members, teachers and friends for not noticing what was going on and trying to help her sooner, as well as the fact that others in her family had experienced mood instability. In addition, the author suggests that taking fluoxetine induced confusing and distressing mixed mood states.

In a second first person account, Amey (2010) writes of her experience of recurrent depression and taking a mixture of antidepressants throughout her life. A combination of two of these, she believes, induced acute psychotic mania as a side-effect. Amey was hospitalised as a consequence of her mania, but this dispersed almost immediately after discontinuing antidepressant medication. She reports that the episode had a marked negative impact on her life and resulted in her feeling unable to continue with her previous professional role.

1.8.3 Qualitative studies

A small number of qualitative studies were found on the topic of bipolar diagnosis. Delmas and Proudfoot (2011) interviewed 17 service users and 9 carers about adjusting to a diagnosis of bipolar disorder and how it may impact on their future. Three key themes were identified: misdiagnosis and how this could affect awareness; acceptance of diagnosis; and how to facilitate acceptance occurring earlier. Practice implications were that accurate, timely diagnosis could facilitate understanding and acceptance, whereas misdiagnosis may delay this process.

Inder and colleagues (2010) thematically analysed data from the psychotherapy sessions of 15 people with bipolar disorder to develop an appreciation of how people come to question, understand and make sense of their diagnosis. They found that the process of being diagnosed was an active one and that factors such as misdiagnosis, questioning of sense of self and medication side effects could lead to mistrust of services resulting in ambivalence and relapse. They concluded that an appreciation of patients' perceptions of a diagnosis of bipolar disorder should be a vital part of therapeutic work.

In another qualitative study, Proudfoot and colleagues (2009) investigated the experiences of 26 service users with newly diagnosed bipolar disorder by analysing their email communications with expert patients as part of an online support programme. They discovered that service users had mixed feelings towards the diagnosis itself, with some experiencing shock, disbelief and anger. Others were relieved at having a way of understanding the difficulties they had been experiencing for a long time. Delayed or misdiagnosis could contribute to both negative and positive feelings of eventually being diagnosed with bipolar disorder. Service users did also question what the diagnosis meant for their self-identity and their future, particularly with regards to the stigma attached to the label. The researchers concluded that the person's attitude towards diagnosis could impact on their treatment engagement and affect prognosis, and that health care professionals should be aware of and work with the issues people experience following a diagnosis of bipolar disorder.

Additional qualitative studies involving service users (and carers) with bipolar disorder where the research topic had less of a focus on diagnosis itself still included some relevant information. Clatworthy and colleagues (2007) interviewed 16 service users and investigated themes related to medication adherence and established that non-acceptance of diagnosis was related to a reluctance to take medication properly. These authors suggested that attitudes to diagnosis

should be explored during interventions to enhance medication compliance. However, a critical view of this study could regard this as a rejection of 'medical model' explanations and interventions overall by some service users.

Similarly, two qualitative studies on the effective management of bipolar disorder (the first collecting written and interview data from 100 participants and the second interviewing 32 participants) cite acceptance and understanding of the diagnosis as two of many strategies which have helped people to cope with the condition (Russell & Brown, 2005; Suto *et al.*, 2010). In a study investigating recovery in bipolar disorder, Veseth and colleagues (2012) interviewed 13 participants who also provided examples of how identifying with a diagnosis had enhanced self-awareness and helped service users to manage their difficulties more effectively.

'... before I got diagnosed, I would just keep going in order to stop myself from falling asleep, but now... I recognize that I am tired and make time for a rest for half an hour, make arrangements for a quiet evening' (In Veseth *et al.*, 2012, p.127)

Michalak and colleagues (2006) interviewed 35 service users (as well as 5 caregivers and 12 health professionals) about quality of life for people with bipolar disorder. They found that whilst a diagnosis could negatively affect a person's self identity, acceptance of the diagnosis could restore self-worth and sense of identity. However, perceived stigma associated with the diagnosis of a mental health condition had a detrimental impact on some participants' quality of life.

1.8.4 Review papers

Elgie and Morselli (2007) considered that service user perspectives in mental health are of significant importance, but are often not considered. In light of this observation, they set out to review available research on the impact of having bipolar disorder on social functioning which took into account a service user, relative or advocacy organisation perspective. They initially carried out a systematic literature search of four computer data bases using a set of relevant search terms (including 'bipolar', 'perspective', 'quality of life' and 'social adaptation'). These searches were then refined to include reports which met the following three criteria: a) they considered the impact of diagnosis on quality of life or social functioning b) the participants involved (or their relatives) were stabilised or not in an acute phase of bipolar and c) research involved structured or semi-structured self-administered questionnaires. On the basis of these,

17 relevant reports were identified which took into account the views of over 6500 individuals in total. A number of conclusions were drawn relating to how being diagnosed with bipolar disorder affected social functioning and family relationships. Of particular relevance to the current study was that delayed diagnosis and incorrect treatment were reported as problems in the majority of studies. People also experienced considerable stigma and discrimination as result of their diagnosis, both socially and within the workplace.

Whilst this review provided a detailed summary of research into the social impact of a bipolar disorder on service users and families, it had a number of limitations. Firstly, the initial search terms used were not particularly comprehensive and could have missed relevant studies. Additionally, the inclusion of only quantitative survey studies could be viewed as a flaw, as valuable data from qualitative studies was omitted. As all studies reviewed included structured questionnaires which were not initially designed by service users, and the fact that there was no inclusion of qualitative comments, it could be considered that true service user perspectives may still not have been represented in this review. However, the type of studies reviewed insured that the responses of a vast number of respondents were taken into account, which would be very difficult to achieve in a review of purely qualitative studies.

The authors concluded that ‘...from the patient’s perspective, the importance of an early and correct diagnosis is paramount...’ (p.153) and that the needs and issues faced by service users should be a focus of future research and service developments.

1.8.5 Survey studies

Postal survey studies have also attempted to represent service user perspectives on various aspects of living with bipolar disorder, and some of these have been reviewed in the paper described in Section 1.8.4. Two surveys particularly relevant to the current study by virtue of their coverage of questions related to diagnosis in particular, as well as their recruitment through charities and advocacy organisations, are the Global Alliance of Mental Illness Advocacy Networks (GAMIAN) - Europe survey (Morselli & Elgie, 2003) and the DBSA survey (Hirschfeld *et al.*, 2003; Lewis, 2001).

The GAMIAN Europe survey included responses from 1041 people with bipolar disorder from 11 European countries, and the DBSA survey study analysed responses from 600 USA-based respondents, and also served as a follow-up to a similar survey promoted by the DBSA almost

10 years previously (Lish *et al.*, 1994). Specific results from these surveys have been reported elsewhere in this review, but a more detailed description of the sections related to diagnosis is given below.

In the GAMIAN Europe survey the mean age of symptom onset was reported to be 25.6 years, with 78.8% of people first experiencing a mood episode before the age of 35, and 33.1% before age 20. A diagnosis was made by a psychiatrist for 70.9% of cases, and by a GP for 17.1%. The mean age of diagnosis was 31.3 years, implying an average delay of 5.7 years. For 43.6% of people the disorder began with a manic episode, for 54.5% it began with a depressed episode. A family history of mental health problems was reported by 64.8% of respondents. Of these, 34.6% reported the presence of bipolar disorder, and 43.6% reported a family history of depression.

In the DBSA survey, 33% of participants' symptoms of bipolar disorder were first experienced when they were less than 15 years old, and an additional 27% experienced them under the age of 20. A family history of bipolar disorder was reported by 45%. Manic symptoms were experienced by 78% of respondents prior to diagnosis, and 83% had symptoms of depression, although symptoms of both were not always reported to professionals. Sleep difficulties were the most frequently experienced symptom and the one for which help was most frequently sought. Over a third of people sought help less than a year after first experiencing symptoms; however, just under a third did not seek help for over 10 years. The most commonly reported reason for help seeking (for 63% of people) was 'symptoms becoming unmanageable'. Help was most frequently sought from a psychiatrist (62%). Over two thirds of respondents reported being misdiagnosed with an average of 3.5 other conditions, and consulting a mean of four doctors, before being diagnosed with bipolar disorder. Most frequently (for 60% of people) this misdiagnosis was depression. Professionals' lack of understanding of bipolar disorder was perceived to be the biggest barrier to correct diagnosis according to 60% of participants. One third of people who were originally misdiagnosed were not accurately diagnosed with bipolar disorder for over 10 years. When the results of the first DBSA survey (Lish *et al.*, 1994) were compared with the results of the second, they were found to be remarkably similar (Hirschfeld *et al.*, 2003) on most variables. This suggests that in the decade spanning from the 1990s to beginning of the 21st century, from a service users' perspective, little has changed in terms of the experience or accuracy of being diagnosed with bipolar disorder.

Both the GAMIAN Europe and DBSA surveys highlight the trend of delayed diagnosis in bipolar disorder and called for improved services for service users. However, although they aimed to gather a service user perspective, qualitative responses on people's experiences were not considered. Service users were also not given the opportunity to comment on how to improve the things they were dissatisfied with.

Lewis (2005) compared the results of the DBSA survey (Hirschfeld *et al.*, 2003) with those of a survey investigating obstacles to managing bipolar disorder effectively from the perspective of 500 psychiatrists (Chengappa & Williams, 2005) in order to highlight the differences between service user and psychiatrist opinions concerning unmet needs. Whilst psychiatrists seemed to rate patient education and support as the highest priority, Lewis suggested that service users view the most important unmet need to be the identification of bipolar disorder and improved education, awareness and understanding of bipolar disorder amongst primary care physicians. Highlighting these differences is valuable. However, the patient view of unmet need was only inferred from the experiences reported in the DBSA survey, rather than explicitly formed in response to a direct question posed to service users.

Lewis (2005) comments that with the best academic knowledge and intentions, healthcare professionals and service providers may not know what is best for service users themselves. This author calls for more collaboration between providers and users in order for both to learn from one another and to for optimum care to be provided. Research aiming to represent service user views on the diagnosis of bipolar disorder suggests that many issues such as delayed and misdiagnosis are indeed relevant to service users to an extent. However, it is important to note that there may also be differences in the true perspectives of service users and those of researchers/clinicians, particularly if research is designed in such a way to obtain the information that the researcher is seeking, or fails to give service users an opportunity to elaborate on their views.

1.8.6 Service user involvement in the design of research

It is important that service users have a genuine voice in research in order to highlight challenges and unmet needs that they face as the key stakeholders in health care (Telford & Faulkner, 2004). However, in order to truly capture a service user and carer perspective, their opinions need to be taken into account at the research design stage (Lewis, 2005). Accordingly,

the BPS emphasise service user involvement in designing research as best practice (Sheldon and Harding, 2010) and user participation in project design is also a priority in psychiatric services (Tait and Lester, 2005). Whilst contributing to research such as randomised controlled trials may not be particularly relevant or useful to service users (Simpson & House, 2003), involvement in research about improving services and the general management of mental health problems may be of more interest to them and enable meaningful and valuable contributions (Telford & Faulkner, 2004).

Despite recommendations, involving service users in research design remains even more of a rarity than properly taking into account service user opinion (McLaughlin, 2010). Of the studies reported previously, Veseth and colleagues (2012) report collaborating with an 'expert by experience' group of 12 people in the design and implementation of their study on recovery and bipolar disorder, which could be viewed as a good practice example. Morselli and Elgie (2003) also reported that 60% of questions included in the GAMIEN Europe survey were suggested by the advocacy groups participating, and the DBSA survey (Hirschfeld *et al.*, 2003) was designed in collaboration with members of the organisation (as well as a research and consulting company), suggesting that for both of these studies the relevant charity members had at least some input into the survey design. The majority of the time, though, research is planned without consulting service users, despite the fact they are the most likely group to be affected by its outcomes (Morselli & Elgie, 2003).

1.9 CURRENT STUDY

1.9.1 Rationale

Considering the literature reviewed, it seems that the delayed diagnosis and misdiagnosis of bipolar disorder is problematic for both services and service users. There are a number of reasons why this may be the case, and there is little sign currently of the situation improving. However, service user views on this topic specifically are sparse or vague, particularly when it comes to the impact of key problems, why they exist and how to make changes and improvements.

Involving service users in the design and planning stages of research is recommended as best practice but happens infrequently. There is also specific guidance suggesting that service users should be involved in designing research carried out by trainee clinical psychologists (BPS,

2008), which applies directly to the researcher. Taking these points into consideration, as part of the current study, a service user focus group was first convened and consulted in order to inform the development of a web-based survey about experiences of diagnosis.

An issue with research which sets out to account for the depth of service user opinion and experience is that it is usually qualitative, rendering it less credible by empirical researchers, and less often published in the peer reviewed domain (Telford & Faulkner, 2004). The current study aimed to overcome this by gathering quantitative survey data from a larger number of participants rather than conducting a typical qualitative study. However, it also sought to capture service user views, both at the design stage and by also including qualitative 'free-text' response questions in the survey. The final question in particular was very general: *'Do you have any other questions, comments or thoughts about any of the issues raised in this survey?'* enabling service users to comment on any aspect of the survey itself or their experience without the constraint of questions directed at certain specific topics. As the survey was anonymous, it was hoped that this would facilitate genuine responses and concerns without respondents feeling inhibited by the social constraints of other face-to-face research methods (Dillman & Smyth, 2007).

Carers, partners and close relatives were also invited to complete a version of the survey as they can often be overlooked in the context of involvement and research (Foster, 2010), and may provide valuable insights into features of bipolar disorder that service users themselves may not recognise.

To the researcher's knowledge, this is the first UK based survey investigating service user and carer views specifically on the diagnosis of bipolar disorder which was designed with the help of service users and included qualitative information within the survey. Previous survey studies investigating service user experiences of diagnosis were carried out almost ten years ago, and included less detailed questions embedded within wider topics on many aspects of living with bipolar disorder. Respondents of these studies were also based in the USA or across Europe (Hirschfeld *et al.*, 2003; Lish *et al.*, 1994; Morselli & Elgie, 2003) and not primarily in the UK.

1.9.2 Clinical Relevance

This study is relevant clinically, as understanding more about the diagnosis of bipolar disorder from a service user perspective has the potential to inform service improvements and the

provision of better care for those affected. By asking service users directly about their experiences, what they think are the main problems and why they exist, as well as their views on how to overcome them, service users can be empowered to express views on the issues which affect them and on where services may fall short of meeting their needs. As the UK policy 'Creating a Patient-led NHS' (DOH, 2005) and the latest Health and Social Care Bill (DOH, 2011) emphasise, service users should be enabled to have a stronger voice, to work in partnership with providers, and to inform the design of their own healthcare.

Because various studies indicate that there are issues with the timely identification of bipolar disorder in general practice (e.g. Smith *et al.*, 2011), it is of clinical relevance to ask service users their views on this situation and their ideas about possible improvements. This is especially topical with regards to the recent focus on provision of mental health services in primary care in England (e.g. Improving Access to Psychological Therapies; See DOH, 2008) and elsewhere in the UK (e.g. Mental Health Measure; National Assembly for Wales, 2010).

With a recent increase in media coverage, and well known celebrities speaking out about bipolar disorder, there is a view that it is becoming fashionable or even desirable to have this diagnosis, and that public and professional awareness of the disorder has increased (Chan & Sireling, 2010). The charity Bipolar UK and the Royal College of Psychiatrists have recently collaborated to develop a brief (six question) public and professional bipolar awareness survey to consider how much people now know about bipolar disorder. The survey will be carried out between April and June 2012 with the aim to gain a UK wide view of people's understanding of bipolar disorder and consider how effectively it is assessed, in order to flag up any key issues (D.Smith, personal communication, March 13, 2012). The current study will therefore contribute a more detailed service user perspective to this line of enquiry.

This survey may also contribute to the debate about the helpfulness and relevance of applying psychiatric diagnoses to mental health distress. Whilst the medical approach tends to dominate the field for bipolar disorder, some argue that such diagnostic labelling is not the most appropriate way of conceptualising the problem (BPS, 2011). However, whilst such a debate may occur between psychiatry and psychology, this study aimed to ask service users, whose views are arguably the most important, what they think about their diagnosis and its impact.

1.9.3 Overall aims

This study aimed firstly to review the literature on the issues in the diagnosis of bipolar disorder in order for the researcher to gain an understanding of the subject area and identify topics which might be usefully explored in the context of a focus group. The second aim was then to consult a service user focus group to inform the development of a web-based survey about service user experiences and opinions on being diagnosed with bipolar disorder. The third aim was to develop and pilot the survey. The final aim was to ask 200-400 service users and carers recruited via the charity Bipolar UK about their experiences of diagnosis, how topical issues apply to them, and their opinions on how services could be improved in the future.

1.9.4 Specific aims

The specific aims of the survey were:

- a) To gain an understanding of service user experiences leading up to being diagnosed with bipolar disorder
- b) To consider whether issues such as delayed and misdiagnosis which have been reported in the research literature are consistent with service user experience
- c) To explore why service users think that any problems they have faced exist
- d) To gain a perspective on how service users think that issues concerning the diagnosis of bipolar disorder can be overcome, specifically in terms of early identifiers and their views on helpful questions that professionals could ask during assessment
- e) To ask service users their views on the usefulness and personal impact of having a diagnosis of bipolar disorder
- f) To include a carer perspective on each of the above aims

CHAPTER 2 - METHODOLOGY

2.0 OVERVIEW

This study employed both qualitative and quantitative methodologies in order to explore service user and carer views and experiences of the diagnosis of bipolar disorder. Initially service users were consulted as part of a focus group on their perspective of key issues in the diagnosis of bipolar disorder. Following this, the qualitative data generated from the focus group was used to develop an online survey generating both quantitative and qualitative data in relation to opinions and experiences of bipolar diagnosis. The following chapter will provide a rationale for the mixed methods approach adopted, as well as describe the design and procedure used to carry out the study. Participant recruitment, materials, ethical considerations and data analysis will also be discussed.

2.1 DESIGN

The design of this study incorporated four main stages.

Stage One: Initially a systematic review of the literature regarding issues, debates and difficulties associated with diagnosing people with bipolar disorder was carried out. Whilst this is described in detail in Chapter One, it is considered to be an important stage of the design as the researcher's awareness of such issues was crucial to the development of subsequent stages.

Stage Two: The second stage involved consulting a service user focus group about their experiences and opinions on the process of receiving a diagnosis of bipolar disorder, as well as their views on the value of having a diagnosis itself. They were also invited to comment on the relevance of certain issues reported in the research literature and to consider questions and responses which they felt would be important to include in a survey about bipolar diagnosis. The qualitative data derived from the focus group was analysed using thematic analysis.

Stage Three: The third stage of the project involved developing an online survey. Themes identified during Stage Two, as well as key issues which emerged from the literature review, were combined in order to design a survey about service user experiences of diagnosis and views on diagnostic issues. The four original focus group members were then asked to pilot the

survey along with the two project supervisors, eight trainee clinical psychologists and two non-psychologists. Feedback was provided and the survey was then amended based on this feedback.

Stage Four: The final stage of the study involved launching and publicising the online survey. There was also an option to complete the same survey (with slight alterations to the wording of the questions) as a carer. The survey collected both quantitative and qualitative data and results were compiled and analysed descriptively using the Bristol Online Survey tool. Quantitative data was further analysed using Excel and SPSS, and qualitative data was analysed using thematic analysis.

2.1.1 Rationale for mixed methods exploratory approach

Mixed qualitative and quantitative research designs can produce a more comprehensive and meaningful picture of the topic under investigation than single method studies (Kelle, 2006). The current project employed a mixed-method, exploratory design in order to combine the qualitative detail of individual service user experience and opinions and consider how these themes could be generalised quantitatively to a greater number of participants. Whilst published research into bipolar disorder is dominated by randomised controlled trials and often funded by the pharmaceutical industry (British Psychological Society, 2010) it is likely to represent the agendas of clinicians and researchers, but not service users themselves. As the majority of this research is quantitative in nature, individual service user experience and opinion is difficult to incorporate. However, experience and opinion is best captured using a qualitative methodology (Willig, 2001), which can be criticised by quantitative researchers for small sample sizes, lack of generalisability and inadequate scientific rigour (Mays & Pope, 2000). By consulting a focus group on their views of relevant issues and of the research design itself, individual service user opinion and experience was captured and incorporated into a survey aimed at a much larger sample size which could be analysed quantitatively, thus combining advantages of both methodologies. The 'free-text' questions and options to add more detailed responses on 'forced-choice' questions meant that people could still freely express their views as part of the survey, generating richer data than a purely quantitative design.

Additionally, consulting a service user focus group in the initial stage of the project meant that their views and opinions on the nature of the research were incorporated and shaped the

direction the survey then took. Thus service user research 'agendas' were considered to be a very important part of the design of the project. Service user involvement in the design of research is good practice and considered to be a priority in mental health services (Sheldon and Harding, 2010; Hayward and Riddell, 2008; Tait and Lester, 2005).

2.1.2 Philosophy and principles of qualitative research

Qualitative research methodologies are increasingly recognised in the field of psychology (Smith, 2008), as they are able to take into account detailed personal, social, historical and cultural factors which can often be lost using more reductionist quantitative methods (Willig, 2008). Qualitative research is designed to capture people's individual perspective on their own experience and gain insight into their unique understanding of the world (Willig, 2008), leading to rich and detailed data on different aspects of human experience. Verbal and written qualitative data can then be analysed in order to identify themes and theories and gain new insights.

2.1.3. Rationale for focus group methodology

Focus groups are considered to be an effective way to determine perceptions, thoughts and feelings of group members (Wilkinson, 2003). They can also generate debate and an opportunity for people to consider and freely express their views on a given topic thus providing rich data (Bloor *et al.*, 2001). Accordingly, a qualitative focus group methodology was chosen for the current study to stimulate discussion and extrapolate service user views and opinions on diagnostic issues. Whilst a standard focus group will have 8-12 members (Oates, 2002), it is thought that a 'mini' focus group, as utilised in the current study, also has advantages. Smaller groups can help members to feel more comfortable, more able to express their views honestly and give each member more time to consider and fully explain their thoughts and perspectives (Krueger & Casey, 2000). In addition, focus groups are considered to be a versatile data collection method which can be used in isolation or as a precursor to quantitative investigations, such as the development of a research instrument (Vaughn *et al.*, 1996).

As well as complementing quantitative methodologies, focus groups are also compatible with a qualitative research paradigm as they adhere to key assumptions of the qualitative approach (Brotherson, 1994). Firstly, the phenomenological nature of reality, in that multiple perspectives

exist, is fundamental to the focus group approach. Diverse opinions and perspectives are not only acknowledged but desired in focus groups. Secondly, the influence of the inquirer and respondent relationship are an important aspect of focus groups, and this relationship, as well as the interactions between participants themselves, can add dimension and depth to the data obtained.

Another advantage of focus groups is that they have the potential to bring the researcher closer to their topic through direct extended conversations with those for whom the research is most relevant (Vaughn *et al.*, 1996). Much valuable information may be gained from intensive interaction with those whose perspectives and experiences are key to understanding a topic (Lederman, 1990). Focus group methodology therefore adheres to current good practice guidance in mental health research by involving and prioritising the views of service users.

2.1.4 Rationale for thematic analysis

Thematic analysis was the method used to analyse the focus groups as well as the qualitative 'free-text' responses obtained in the survey. The principles and rationale for this approach are described below. An explanation of how the analysis was carried out is provided in Section 2.5.1.

Thematic analysis is a flexible, qualitative method of analysing data which focuses on reporting patterns, commonalities and themes and providing a detailed yet organised account of a data set (Braun and Clarke, 2006). It is also a method which is free of a particular theoretical stance, unlike other qualitative methods such as Grounded Theory (Anselm and Corbin, 1998) or Interpretative Phenomenological Analysis (Smith and Osborn, 2003). This lack of epistemological constraint increases its versatility as a research tool, meaning it can be applied to different types of qualitative data (Braun and Clarke, 2006). For this reason, thematic analysis was deemed an appropriate method to use in the current study which requires flexibility to apply themes derived from the focus group to the design of a survey. In addition, it is considered to be useful when working in a format where participants are also collaborators in the research design (Braun and Clarke, 2006). Due to its versatility, thematic analysis was also considered to be appropriate to apply to the qualitative written data derived from the survey.

However, whilst widely used in psychology, thematic analysis has been criticised for being poorly demarcated, with little clear guidance on how it is carried out. In Braun and Clarke's (2006) paper, they seek to answer this criticism by providing a practical guide for researchers to engage in thematic analysis in a theoretically and methodologically sound way, whilst not losing any of the flexibility that the approach benefits from. They also recognise the researcher as an active participator in the process of analysis and recommend that this procedure is clearly described (see Section 2.5.1). This paper was therefore used to guide the thematic analysis process for both the focus group data and qualitative survey data in the current study.

Braun and Clarke (2006) also consider that whilst thematic analysis is not constrained by a specific epistemological background, researchers will still hold a particular position in relation to the data and this should be stated. For the thematic analysis carried out in the current study, the researcher held an essentialist-realist stance (that participant experiences, opinions and meanings discussed were a part of their reality) as opposed to a more constructivist one (which reflects more on the impact discourses in society have on events, experiences and meanings). This essentialist-realist stance led to the mixed methods approach adopted in this study, and was appropriate when analysing the focus group for more concrete themes to inform specific survey questions and possible response options.

The approach taken to analysis was also a deductive/theoretical one, meaning that it was driven by the researcher's pre-existing theoretical interest in the area and participant responses to particular questions (Boyatzis, 1998). This differs from a more inductive approach, where the analysis is driven by the data itself rather than by pre-existing ideas. A theoretical approach was considered most appropriate given the initial literature review stage of the study (which provided the researcher with a theoretical grounding in the area of bipolar disorder diagnosis) and the intention to combine focus group themes with pre-existing knowledge to develop the survey. Also of relevance to this, it has been suggested that familiarisation with the relevant research literature prior to carrying out thematic analysis can enhance the process and increase awareness of more subtle data features (Tuckett, 2005).

2.1.5 Ensuring Quality

Qualitative methodology has grown in popularity over recent years with the number of academic journals specialising in such research methods dramatically increasing (Denzin & Lincoln,

2005). Accordingly, the legitimacy, reliability and validity of qualitative approaches have come under more rigorous scrutiny. Following a review of relevant literature and peer feedback, Elliott and colleagues (1999) devised a set of guidelines to establish a degree of quality control in qualitative research investigations. These are detailed below with an explanation of how the current study adheres to the recommendations.

- **Owning one's perspective** – The researcher should not only specify their theoretical orientations but also disclose the values, interests and assumptions they may have derived from their experiences. It should be acknowledged that these preconceived ideas may play a role in the researcher's understanding of the data, hence informing the reader's interpretation of the results. Please see Section 2.1.6 for a description of the researcher's background, perspective and experience relating to the diagnosis of bipolar disorder. The aim of this is to be transparent about how these factors may inform the research process.
- **Situating the sample** – The researcher should provide basic descriptive data about the participants, their circumstances and their experiences in relation to the topic under investigation. The aim of this is to provide a summary to enable the reader to consider how far results can be generalised to other people and situations. This was adhered to in the current study by providing demographic information and a brief description of focus group participants which can be found in Section 2.2.1.5.
- **Grounding in examples** – The researcher should provide some excerpts of data, as well as being transparent about the analytic procedure and how a particular understanding or conclusion is drawn. This enables the reader to evaluate this process as well as to draw out their own alternative interpretations. In the current study, relevant data examples and the sub-themes and themes drawn from them will be described fully in Chapter Three. It will also be shown how these then became applicable to the survey development in Section 5.1. Transcript extracts will also be provided in Appendix B.
- **Providing credibility checks** – Researchers should use methods to check the credibility of their themes, to ensure that their understanding appropriately represents the data. In the current study this was carried out in a number of ways. Firstly, the survey was developed using themes derived from the focus group data. Focus group members were then asked to pilot the survey and to report anything which they thought needed

amending or that did not accurately reflect the ideas and views they expressed in the focus group. Secondly, survey questions and themes were discussed with project supervisors, one of whom is regarded as an expert in the bipolar disorder field. Thirdly, transcripts and the thematic analysis process were also checked and corroborated by a trainee clinical psychologist colleague who also used this methodology as part of his doctoral research on a different topic. Finally, focus group ideas and themes were 'triangulated' with existing research in the area to ensure that survey questions were relevant to both published research and service user views.

- **Coherence** – The data must fit together and be described in a way which is coherent, understandable and adds clarity without losing the finer detail of the data set. The current study attempted to do this by summarising the themes and sub-themes in written form (See Chapter Three) as well as organising them into a survey format (See Appendix C).
- **Accomplishing general versus specific research tasks** – The researcher should maintain consideration of the limitations of their analysis in terms of generalisability. If the understanding of a phenomenon is intended to be general, it needs to be informed by an appropriate range of participants and situations. If the understanding is intended to be more specific to a particular case or situation, then this must be analysed comprehensively and systematically. The qualitative aspect of the current study included only four focus group participants, but the intention was to be able to use the themes derived from this to ask a much larger number of participants their views on the same topics. From the survey results it was then possible to consider how these themes applied (or conversely, did not apply) more generally to people's experience of the diagnosis of bipolar disorder. Limitations of the design, data and analysis will be discussed in more detail in Section 5.4.
- **Resonating with the reader** – The researcher should present their report in such a way that it resonates with the reader. It should be perceived to accurately represent the subject matter which it describes, as well as bringing greater understanding and meaning to the topic. The researcher aimed to keep this in mind throughout the thesis writing process.

2.1.6 The position of the researcher

Reflexivity is also an important aspect of qualitative research, meaning that the researcher should acknowledge and retain awareness of the impossibility of remaining completely impartial to the data (Willig, 2001). Accordingly, as explained in Section 2.1.5, understanding the researcher's perspective is important for ensuring transparency about anything which may influence interpretation of the data. A brief description of the researcher's background and interest in the subject matter is provided below.

The researcher is a white, unmarried 31 year old female who was born and spent most of her childhood in a rural area of South West England, but has lived in a South Wales city for 10 of the last 12 years. The current study is being carried out as part of a Doctorate in Clinical Psychology qualification. As part of this course, the researcher also completed four varied clinical placements and at time of write up was working on a fifth placement in an Adult Mental Health Specialist Eating Disorders Service.

The researcher has always had an interest in the accuracy and relevance of psychiatric diagnoses, particularly in the areas of eating and mood disorders. The researcher is also interested in the dominance of psychiatry regarding the research, assessment, diagnoses and treatment of certain mental health problems, such as bipolar disorder. As a psychologist the researcher is also curious about the 'anti-psychiatry' position, and is keen to know about service user views on this apparent dichotomy.

The researcher has encountered three people with bipolar disorder in a professional capacity, but also knows approximately five people with the diagnosis personally. These individuals have a variety of perspectives on and relationships with their diagnosis. Their views range from a denial of the existence of any problems, to a belief that their difficulties irreparable and entirely out of their control. People also have a variety of attitudes to services, from complete avoidance, to a critical but grudging acceptance of help, to extremely positive reports of treatment and support from healthcare professionals. Most pertinent to the current study was the researcher's experience of having a housemate who was diagnosed with bipolar disorder during the time period that they lived together. The researcher was very aware of this person's struggle to cope with and understand their difficulties, as well as the problems they faced getting healthcare professionals to take them seriously. Prior to diagnosis with bipolar disorder, it was assumed by this person's GP that they primarily had low mood and were dependent on alcohol.

The researcher was aware that this previous knowledge and experience of bipolar disorder might influence the analysis of the data, so efforts were made to maintain a neutral and open-minded stance and to consider all different perspectives and ideas equally.

2.1.7 Rationale for internet based survey

As internet use has become commonplace in almost all segments of society, web-based survey designs are becoming increasingly widespread in both public/private enterprise as well as scientific research (Dahlberg, 2007). They can also offer a number of advantages over pen and paper, telephone or face-to-face lines of enquiry (Heiervang & Goodman, 2011).

An internet survey design was chosen for the current study for a number of reasons. Firstly, it represented a time and cost-effective method of obtaining views and opinions from a relatively large sample of participants. Online surveys enable researchers to reach hundreds of people, possibly separated by considerable geographical distances, in a short amount of time (Taylor, 2000). Internet research is also much more cost effective than face-to-face or paper methods, which can be resource heavy when researcher time, travel expenses, paper, printing, postage, data entry and various other costs are all involved (Llieva *et al.*, 2002).

As well as saving time and money for the researcher, internet surveys are also more convenient for participants, as they are not required to travel anywhere and can complete the survey in their own time, without having to meet with anyone, or have the inconvenience of considering how questionnaires need to be returned. Internet surveys are also advantageous as they provide a greater level of anonymity. Information which could identify a participant does not need to be collected, and the Bristol Online Survey tool used in this study does not retain any information about the computer which was used to complete the survey, ensuring complete anonymity.

Due to their anonymous nature, web-based surveys can provide a method of connecting with difficult-to-access populations, such as those with mental health problems who may be reluctant to speak out 'offline' for fear of being stigmatised (Wright, 2005). They also offer the opportunity for people to express their views who may otherwise be hesitant to meet face-to-face due to having extreme or controversial opinions. Additionally, participants may feel they have greater freedom to express their opinions rather than giving socially desirable responses (Dillman & Smyth, 2007).

Research also suggests that the internet is increasingly used as a resource by mental health service users, who find it advantageous due to it offering them convenience, privacy and anonymity (Powell & Clarke, 2007). It was therefore considered that an internet survey would be an appropriate method of engaging service users with bipolar disorder in research.

It is important to acknowledge that internet surveys also face a number of ethical considerations which will be addressed in Section 2.4.1.2, as well as other criticisms such as sampling issues which will be discussed in Section 5.4.3.

2.2 PARTICIPANTS

The researcher wanted to reach a large population of people with a diagnosis of bipolar disorder for the survey stage of the project. Rather than recruiting via individual Community Mental Health Teams and other NHS services, it was decided that the best way to invite large numbers of service users to take part was to approach a significant bipolar disorder charity. Participants were therefore recruited via 'Bipolar UK' (a charity dedicated to supporting people with bipolar disorder, their families and their carers – formerly known as 'MDF – The Bipolar Organisation'). This is the largest service user led bipolar charity in the UK, with a membership of several thousand. The Cardiff University Mood Disorders Research Group also has access to a list of South Wales based people who have previously volunteered to take part in research and expressed an interest in future research studies, so this resource was also used to recruit local focus group participants.

2.2.1 Focus group participants

2.2.1.1 Recruitment

Focus group participants were recruited via the Welsh branch of Bipolar UK and via the Cardiff University Mood Disorders Research Group. Bipolar UK self-help group facilitators were approached via email with information about the focus group, and were given the option for the researcher to attend the group and explain the study to group members, or to pass on information sheets and consent forms (See Appendices D and E) to group members themselves. Previous research participants of the Cardiff University Mood Disorders Research Group were also emailed information about the focus groups. Potential participants were then

invited to contact the researcher via email or on a project specific phone number to arrange group attendance. Due to the focus group meeting being held in Cardiff, only people based in the local area were approached to avoid any participants having to travel long distances.

2.2.1.2 Inclusion criteria

Participants had to be aged over 18 and to have a self-reported diagnosis of a bipolar spectrum disorder (or be a family member or carer of someone with a diagnosis of bipolar disorder). Participants also had to have the capacity to understand and to consent to taking part in the research, the ability to take part in a focus group, and the ability to speak and understand English.

2.2.1.3 Exclusion criteria

Participants could not be under the influence of alcohol or non-prescription drugs and could not be currently experiencing a manic episode which would interfere with their ability to constructively participate in the focus group.

2.2.1.4 Participants recruited

Six participants (five service users and one carer) contacted the researcher to take part in the focus group. One service user was unwell on the day of the group so did not attend, and the carer could not attend at the last minute due to work commitments. Four service users therefore took part in the focus group.

2.2.1.5 Situating the sample – participant pen portraits

As indicated in Section 2.1.5, it is important to include a brief description of focus group participants in order to consider the range of people the findings may be relevant to. Pseudonymised participant profiles are therefore provided below.

- **‘Siwan’** – Siwan is a 68 year old white Welsh woman. She is currently retired, and has a post-graduate degree. Siwan was diagnosed with bipolar disorder in 2003 (the type was not specified). Siwan considers on reflection that she was misdiagnosed with unipolar depression following a hysterectomy 16 years before she was eventually diagnosed with bipolar disorder. This diagnosis occurred when Siwan was admitted to hospital during an episode of mania. She is involved in mental health service development as a service user representative.
- **‘Elanor’** – Elanor is a 40 year old white Welsh woman who lives with her husband and 11 year old son. She is currently employed full-time. She was first diagnosed with bipolar I in 2001. This followed an episode of puerperal psychosis after the birth of her son during which she was hospitalised. When Elanor experiences mania she finds that she continues to experience psychotic symptoms and knows that she lacks insight at these times. Elanor is proud of how she manages her difficulties and sees herself as a stronger person because of it. She sees acceptance as the key to living a normal life.
- **‘Jacob’** – is a 40 year old white Welsh male who is employed full-time and has a post-graduate degree. He was first diagnosed with bipolar I in 2001 after being hospitalised during a manic episode. Initially it was thought that he had schizophrenia, but this was changed to bipolar disorder during the same inpatient stay. Jacob was hospitalised once more six months after his initial episode, but now feels he has his symptoms under control and can access help when he needs it. He attends a Bipolar UK self-help group regularly and finds this to be a good source of support and education about bipolar disorder.
- **‘David’** – David is a 42 year old white British male who is currently self-employed. David is separated from his wife and has a 16 year old daughter and 11 year old son. David describes going repeatedly to the doctors for 10 years and being diagnosed with depression before first being diagnosed with bipolar II in 1999. Before this time he struggled with bad reactions to antidepressants. David wishes he had been diagnosed sooner with bipolar disorder as the symptoms which he previously didn’t understand affected both his marriage and his career. David, like Siwan, is also very involved with services professionally as a service user.

2.2.2 Survey participants

2.2.2.1 Recruitment

Survey participants were recruited primarily via Bipolar UK following an email invitation to take part in the survey sent out to UK-wide members by charity chief executive Suzanne Hudson.

2.2.2.2 Inclusion criteria

Participants had to be aged over 18 and had to have a self-reported diagnosis of a bipolar spectrum disorder (or be a family member or carer of someone with a diagnosis of bipolar disorder). Participants had to have the capacity to understand and to consent to taking part in the research, the ability to complete an internet-based survey, and the ability read and write English.

2.2.2.3 Exclusion criteria

There were no exclusion criteria for this part of the study. This was because, if a potential participant were to access the link for the survey, providing that they agreed to four consent statements following the information page (See Appendices F and G) there would be no way of preventing them from completing the survey.

2.2.2.4 Participants recruited

Based on the premise that approximately two thousand people would be contacted about the survey via email or have access to publicity material, it was expected that approximately 10-20% (in line with response rates of similar studies - Hamilton, 2009) of these would opt to complete the survey, giving an anticipated sample size in the region of 200 to 400 survey participants. In total 262 service users and 65 carers completed the survey.

2.3 MATERIALS

2.3.1 Focus group materials

2.3.1.1 *Demographic questionnaire*

Focus group participants were asked to complete a simple demographics questionnaire. This asked participants for their date of birth, ethnicity, employment status, education level, type of bipolar diagnosis and the date their diagnosis was first given (See Appendix H).

2.3.1.2 *Focus group schedule*

The focus group interview schedule followed a semi-structured approach, which is considered to be flexible in allowing ideas to emerge which can then be pursued by the researcher (Charmaz, 2003). The researcher's prior knowledge of the subject area was important using this approach, as it allowed for ideas suggested by participants to be explored in greater depth.

The researcher drew on researched topics relevant to the diagnosis of bipolar disorder as well as the experiences of acquaintances with bipolar disorder to compile a focus group interview guide. The main topic areas and key questions explored are outlined below. Subsidiary questions were also asked depending on participant responses to the main questions in order to explore their views and perceptions in more detail. Frequently this would lead onto additional topics, but this discourse was not discouraged as long as the content did not become completely irrelevant to the focus group purpose.

- **Value of diagnosis:** How helpful is being diagnosed with bipolar disorder? What are the advantages and disadvantages of receiving a diagnosis?
- **Issues in diagnosis:** What are the issues in people's experiences of getting a diagnosis? Do over-diagnosis, under-diagnosis, misdiagnosis, early diagnosis or delayed diagnosis cause problems for people?
- **Help-seeking:** What aspects of bipolar disorder are most likely to encourage people to seek help? Who should they go to for help? What prevents people from getting the right help?

- **Warning signs:** What are the most important symptoms or warning signs which would give others a clue that someone had bipolar disorder? What were the things that people noticed before they were diagnosed? What did other people notice?
- **Professionals and services:** How much do GPs know about bipolar disorder? How about other healthcare professionals? What are the most important/useful questions a healthcare professional could ask to help them identify whether someone had bipolar disorder?
- **Survey Design:** What would be the most important questions to include in a survey on bipolar diagnosis? Are there any other views on the way the survey might be designed?

2.3.2 Survey

The survey was created using the Bristol Online Survey (BOS) tool (www.survey.bris.ac.uk) for which Cardiff University has an organisational licence, enabling staff and students to utilise the service free of charge for research purposes. In order to be issued with a BOS account, the researcher was required to go on a three hour training course on survey design and the use of the BOS tool. The service allows users to develop, launch and analyse surveys via the web. It has the facility to collect and store data securely and anonymously, and also does not store any information about the particular computers (e.g. cookies) used to complete surveys.

The survey was presented to participants online after they followed a website link included in the email publicity material (Appendix I). Initially participants were presented with an information page (See Appendix F) which they were required to read through before selecting 'continue'. This was then followed by a consent page (See Appendix G), where participants were required to agree to the four consent statements before continuing on to the next page to complete the actual survey questions.

Survey design was guided by recommendations outlined by Leong and Austin (2006) regarding layout and question organisation. They also suggested that questions need to be polite and appropriate, clear and precise, unbiased and cautious when seeking sensitive information. These factors were all taken into consideration when developing the survey.

The final survey included 25 questions (some with more than one section) and took approximately 30 minutes to complete. The survey included seven questions on demographic information and one question about bipolar disorder criteria in order to validate self-reported diagnosis. The remaining questions asked about: pre-diagnosis experiences, pre-diagnosis warning signs, help seeking, the experience of obtaining a diagnosis, barriers to diagnosis, alternative diagnoses, views on the general understanding of bipolar disorder, ideas for improving services, and thoughts on the value of the diagnosis itself (See Appendix C for a template of the full survey).

The majority of the questions were 'forced-choice', where participants were required to choose an answer or a number of answers from a pre-defined list of choices. The rationale for this was that too many free text questions can deter people from taking part in or completing a survey (Crawford *et al.*, 2001). These response options were generated from themes derived from the focus group discussion. However, most questions included an 'other' option and a space for free text comments if participants wished to elaborate further. There were also two other free text questions, one on a more specific topic considered to be very relevant to the survey ('Do you have any other ideas about the most useful questions GPs could ask to help them identify whether someone has bipolar disorder?') and one as a general space for extra thoughts and views ('Do you have any other questions, comments or thoughts about any of the issues raised in this survey?'). For both these questions a response was 'optional', meaning that participants could submit the survey without providing an answer for either. For other questions participants were required to provide at least some answer, even if this was 'I don't know' or 'not applicable'. The BOS tool enabled the survey to be presented in an easy-to-read, accessible and usable format, with most questions just requiring the click of a button to make the process as straightforward as possible for participants.

There was an additional version of the survey for carers which could be accessed by following a separate link. This survey included 25 questions addressing the same content as the service user survey, but reworded where appropriate to ask about the experiences of the person they care for rather than asking about first person experiences. The exception was that the question about diagnostic criteria was replaced by a question about how long they had known the person they care for, and whether they had known them 'pre-diagnosis'.

After completing the survey, participants were required to click 'submit' in order to register their answers. This then took them to a final 'Thank-You' page which also included the researcher's contact details should they have any further questions about the survey.

2.4 PROCEDURE

2.4.1 Ethical considerations

The welfare of participants was considered to be of paramount importance during the course of this project and all research activity was guided by the general ethical principles of the British Psychological Society (2011b) as well as their document 'Conducting Research on the Internet: Guidelines for Ethical Practice in Psychological Research Online' (2007). Prior to commencement, the project was reviewed and approved by the Cardiff University School of Psychology Research Ethics Committee (See Appendix J) as well as the Cardiff and Vale University Local Health Board research and development department (See Appendix K).

2.4.1.1 Focus group considerations

Participation in the study was voluntary. Prior to taking part in the study, all potential participants were given an information sheet about the purpose of the study and what would be involved (See Appendix D). This reminded participants of steps taken to ensure confidentiality and explained that the focus group would be audio recorded, but that this would be transcribed using pseudonyms and that all personally identifying data would be removed and the audio recordings then destroyed. The information sheet also reminded participants that they could withdraw from the group at any time and that any data they had already provided would also be omitted if requested. It was also made clear to participants that if they became distressed during the discussions for any reason they could leave the group. They would then be given the opportunity to have a private conversation with the facilitator after the group and would be signposted to additional support organisations. These points were reiterated verbally by the researcher before the focus group discussion commenced. Participants were also invited to ask any questions or to voice any concerns that they may have had. When participants were satisfied they were asked to sign a consent form (See Appendix E) before the focus group began. Participants' travel expenses were reimbursed and they were given a shopping voucher as a token of appreciation for giving up their time.

The information sheet also explained to participants that they would be asked if they were happy to be contacted in order to pilot the survey that would be developed following the focus group. All participants agreed to be contacted via email for this purpose.

2.4.1.2 Survey considerations

Participation in this aspect of the study was also entirely voluntary. Potential participants who were interested in completing the survey were required to follow a website link which took them straight to the survey information page (See Appendix F). This page outlined the purpose of the study and what completing the survey would involve. It also explained that responses would be completely anonymous and that there would be no way of tracing data back to individual participants or the computer from which the survey was submitted. Participants were also informed that they could withdraw at any time by simply not completing the survey and that in such circumstances their data would not be used. Participants who submitted the survey and then wished for their data to be withdrawn were told that they could contact the researcher with the date and time they completed the survey in order for their specific responses to be removed.

Researcher contact details were provided on the information page to enable participants to ask any questions about the research before taking part. When satisfied, participants were able to then continue to the consent statements on the following page (See Appendix G). Participants were not able to continue on to the survey questions without first agreeing to four consent statements. Researcher contact details were also included on the final page of the survey for the purposes of withdrawal or if any participant had additional questions or wanted to discuss the research further with someone. The researcher was then able to signpost participants to support organisations if necessary. As the survey was available freely on the internet, in order to preserve the researcher's safety and privacy, contact details provided were a professional email address and a study specific phone number.

The absence of physical contact between the researcher and participant in internet mediated research gives rise to a number of additional ethical considerations (See BPS, 2007). Those relevant to the current study are discussed below.

Despite information and consent pages being included in online research there is no way to ensure that these have been adequately read and understood. Indeed, internet users may have a tendency to skim over such information in a similar manner to skipping website terms and conditions and simply ticking the agreement box. In this case, consent would be provided, but it may not be informed. The current study aimed to minimise this difficulty by designing the information page to be as user friendly as possible. Each point was made following a bold question heading in order for participants to easily access the things they needed to know. However, the information page was also, for ethical reasons, required to cover a number of different points, meaning that there was still a lot of information which participants were expected to read on one page.

Verification of identity is another difficulty with internet based research. There is no way of knowing that the participants are who they say they are or that they have the characteristics needed for valid inclusion in the survey sample. Most relevant to this in the current study is the fact that participants are expected to either have a diagnosis of bipolar disorder or care for someone with this diagnosis. Attempts were made to overcome this potential problem in a number of ways. Firstly, the survey links were only sent out via groups that have an exclusive membership of people with bipolar disorder (and their carers) so others would be unlikely to come across the survey. Secondly, if they did, they would be likely to lose interest very quickly as most questions would be irrelevant to them. Thirdly, the service user version of the survey also included a question which asked participants about their experience of symptoms in line with diagnostic criteria for bipolar disorder (DSM-IV-TR, 2000). Anyone without bipolar disorder would be unlikely to respond to these questions appropriately which would identify them as not having bipolar disorder.

Data protection legislation is an additional consideration which is relevant to most psychological research due to the collection of participant data which is considered to be of a personal nature (for example, information about mental health problems). For research conducted on the internet, additional considerations are necessary, including lodging a notification of the online research. The current study was registered with and authorised by the Cardiff University Data Protection Controller. The survey information page also informed participants that their data would be controlled by Cardiff University, held securely by the survey software provider (Bristol University) under contract, and then retained by Cardiff University in Accordance with the Data Protection Act (1998).

2.4.2 Focus group procedure

The focus group was held in a meeting room at a Cardiff based Arts Centre. This venue was chosen as it is also used by Bipolar UK to hold regular self-help groups, so it was hoped that it would be familiar to participants. On arrival, participants were given an opportunity to re-read the information sheet (Appendix D) and to ask any questions. They were then given a consent form to sign (Appendix E) and a brief demographic questionnaire to complete (Appendix H). Following this, the researcher outlined the purpose of the group. Practicalities and informal group rules were then explained before the main discussion began.

The approach taken by the researcher aimed to be sensitive to the experiences and views of individuals in the group and inclusive of all those who wanted to express a view on a particular topic. Refreshments were available for participants to help themselves to during the course of the group in order to help them feel comfortable, and people were also invited to take a break half way through.

The focus group discussion took approximately two hours and was taped using a digital audio recording device, which all participants agreed to as part of the consent process. This recording was then transcribed verbatim by the researcher. Care was taken to remove all participant identifiable data from the resulting transcript. Participants were given the opportunity to contact the researcher following the focus group with any additional questions or comments.

2.4.3 Survey development and piloting

Following the focus group, the transcripts were analysed using thematic analysis (See Chapter Three for detailed results) and the themes derived were then combined with topics pertinent in the current research literature in order to develop a set of questions. These aimed to ask about people's personal experiences of being diagnosed with bipolar disorder as well as their views on current issues in diagnosis. A pilot survey internet link was then emailed to the four original focus group members for feedback, and to ensure that their views had been appropriately represented. The pilot survey was also emailed to the two project supervisors (one consultant clinical psychologist and one consultant psychiatrist), eight trainee clinical psychologists and two other non-psychologists. All those contacted indicated that they were generally satisfied with the content of the survey, and most feedback provided related to specific question wording or

layout. This led to some minor amendments before the survey was checked a second time by project supervisors. The carers' version of the survey was also checked through at this stage.

2.4.4 Launching the survey

The finalised survey was then launched online on 12th Dec 2011 and could be easily accessed via specific links. The links were included in publicity material (See Appendix I) sent out via email to Bipolar UK members. Following the survey link would take participants to the initial information page of the survey. The survey was available online for two months, until 12th February 2012, to give people plenty of time to complete the survey despite the busy Christmas period. The researcher did not have any direct access to survey participant contact details at any stage. The BOS tool collected, stored and collated participant responses as they were submitted allowing the researcher to monitor survey completion figures during the two month time period.

2.5 DATA ANALYSIS

2.5.1 Focus group – thematic analysis

As explained in Section 2.1.4, thematic analysis was selected as the most appropriate method of analysis for the focus group data. The guidelines described in Braun and Clarke (2006) were followed for the purposes of this study and are summarised below.

- **Phase 1: Familiarisation with the data** – This involves immersion in the data, becoming familiar with the depth and breadth of it, and repeated reading whilst actively searching for ideas and meanings. The process of transcription is thought to be a good way to become closely acquainted with the data, and has even been described by some as fundamental to the analysis (Bird, 2005). Accordingly, the researcher transcribed focus group data personally, and ensured that time and care was taken over this process to deepen understanding. The transcript was also checked back against the original recording to ensure accuracy and further aid familiarisation (see Appendix B for transcript extracts).

- **Phase 2: Generating initial codes** – This stage involves identifying codes. These are in essence the most basic features of the raw data which are of interest to the researcher, and begin to organise the data into meaningful groups (Tuckett, 2005). The researcher carried out this process systematically, giving equal attention to each item. Items which seemed to oppose the dominant discourse were also retained to broaden understanding. The researcher adopted a ‘theory-driven’ approach, having specific questions in mind which they aimed to code around.
- **Phase 3: Searching for themes** – This stage involves focussing at a broader level, and beginning to combine and collate codes into possible themes, then ensuring that all relevant data for each suggested theme is included. The researcher carried this out by numbering and grouping codes to establish a set of themes.
- **Phase 4: Reviewing themes** – The purpose of this phase is to review and refine themes to ensure that they fit together in a meaningful way whilst being distinct from each other. This process was carried out by first considering whether the coded data extracts belonging to a theme fit coherently, and then either revising the theme or moving the code somewhere else accordingly. Once this was carried out with all the possible themes, the second stage involved considering how they fitted together to make overall sense of the data. The transcript was also re-read at this stage to ensure the emerging themes appeared to fit with the original data set.
- **Phase 5: Defining and naming themes** – This aim of this stage is to continue the analysis of the themes and clearly define and name them in a way which captures what is interesting about them. To illustrate this in the current study, a description of each theme and their narrative, as well as how they fitted into the overall analysis, is presented in Chapter Three.
- **Phase 6: Producing the report** – Writing the report involves an in depth description of the thematic analysis which also highlights its importance and relevance. The thematic analysis in the current study is written up in Chapter Three, and includes extracts demonstrating each theme and a thematic summary table. An explanation of how the themes were used to develop the survey is provided in Section 5.1.

2.5.2 Survey analysis and data handling

The BOS tool collected survey data and provided a basic descriptive analysis. For a more in-depth analysis, quantitative data was exported into SPSS/Microsoft Excel. Most data was analysed descriptively in detail with graphical representations to aid clarity. Qualitative data gathered in the survey was analysed using thematic analysis as described in Section 2.5.1.

For 12 questions (or parts of questions) out of 25, a predefined list of possible responses were given with the option of including answers not already listed by selecting 'other' and then responding in a 'free-text' window. For the questions asking about more concrete topics, e.g. (9a, 12a, 12b, 13a, 13b, 15b) 'who did you first go to for help with bipolar symptoms' or 'what previous diagnoses were you given', 'Other' responses were analysed by coding them as additional response categories, with similar responses being coded together. For questions where people were only able to select one response, any free-text responses which fit best into already defined categories were recoded as such, although some categories were reworded or grouped together to describe the data in the most appropriate way (e.g. Q12a and Q15b).

Example 1 (See Q9a/Section 4.2.2.1): Were these early signs [of bipolar disorder] most similar to: a) mania/high mood, b) hypomania (less extreme mania), c) depression/low mood, d) a mix of high and low moods/extreme mood swings, e) other. Other categories based on additional free text responses were a) anxiety symptoms, b) psychosis and c) autism-like features. Comments about agoraphobia, being 'keyed up' and panic attacks were all coded as anxiety symptoms. Comments such as 'suffered depression since about 18 years old' were recoded as c) depression/low mood.

For questions about more abstract topics e.g. (12c, 14a, 17, 18, 24a and 24b) 'what do you think were barriers to identifying the problem sooner?' or 'has a diagnosis of bipolar disorder been helpful to you in any of the following ways?' where more detailed 'Other' qualitative responses were given in addition to selecting items in the response list, general additional themes will be described. Providing exact numbers for themes/categories occurring in these types of questions was decided to be unnecessary for three reasons. Firstly, many responses were elaborations on pre-defined response options that had already also been selected, meaning that there would be some duplication. Secondly, some respondents provided a level of detail and a number of points within one response which could not adequately be reduced into single categories which could be counted. Thirdly, each response theme applied to few people

compared to the numbers of predefined responses which had already been selected. However, if they had been available options, it is possible that more people may have selected them due to the 'select all that apply' directions for these questions, meaning that any 'count' of similar responses may be inaccurate.

On occasions when free-text comments would go into greater detail than required by the specific question, in order for this information not to be lost, these responses were included in the thematic analysis of the responses to Question 25, which was an open question asking people to comment on any of the issues raised in the survey.

For the carers' survey, all questions included the option of 'don't know'. For some responses which are reported as percentages for the service user data, where there are a significant number of 'don't know' responses from carers these will be described without citing numbers.

CHAPTER 3 – RESULTS: FOCUS GROUP

3.0 OVERVIEW

The focus group transcript was analysed using thematic analysis. Seven key themes and a number of sub-themes were identified relating to service users' experiences of being diagnosed with bipolar disorder and their views on service improvements. These are outlined in Table 3.1 (p.76). The themes and sub-themes are explained in greater detail below, and selected quotes relating to each are also presented. For an excerpt of the focus group transcript please see Appendix B.

3.1 EXPLANATION OF THEMES

3.1.1 Meaning and implications of a bipolar diagnosis

Participants all gave examples of how being diagnosed with bipolar disorder has had an impact on the way they view themselves, the way they understand their experiences, the way others may view them, and how they are able to live their lives. The diagnosis could have both positive and negative meanings.

Empowering versus self-limiting

Participants considered that having a diagnosis could affect the way in which they viewed themselves. It could serve as a way of seeing themselves as stronger and more empowered by being able to cope with the adversity that having bipolar disorder could bring. However, they considered that the confinements of a diagnosis could also be self-limiting, leading them to believe that they are not capable of doing certain things because of the diagnosis.

Elanor: I tell everybody, my boss says I wear it as badge almost ... 'she's a perfectly normal person, but she's got this illness, and she copes'. I'm kind of proud of how I cope with it.

David: I think it's possible that we may use it as a limiting belief, self handicapping kind of thing. There might be opportunities available or open to us, social ones, work related ones, study related ones, and we

might just think, I can't do that because I'm a ... or I've got ... so I think sometimes it can be limiting to ourselves if we live within the barriers we put around ourselves, as having a diagnosis.

Chronic condition

Participants all held the view that having a diagnosis of bipolar disorder meant that they had a life-long condition. This view was considered in both a negative light (in the sense that they were a 'lost cause') as well as more positively (the idea that accepting this was part of self-management):

David: A lot of the literature, and scientists, they say it's a severe and enduring mental health condition, basically, you're written off, essentially. It's not like your leg breaks, you fix it and you're good as new.

Jacob: I think the first time I got diagnosed and the psychiatrist took me off the tablets and discharged me, I was like 'I've got bipolar and I feel great, I've got better'. Six months later, I'm having another high. So ever since then, I know, it's at the back of my mind, I've got this, and I look for the triggers, but it doesn't dominate my life.

Making sense of experiences

Participants thought that receiving a diagnosis could be reassuring, and act as a way to understand and make sense of the symptoms they had been experiencing:

Siwan: I mean, I think a diagnosis is helpful because it crystallises what's happened, you actually know what the situation is. I find it much easier to know about something, than to be wondering, 'what is this?' I'm the sort of person who needs to know things, and then you can act accordingly.

Opening doors to support

Participants had all experienced increased access to appropriate help and support as an advantage of having a diagnosis. Two participants also gave examples of how making colleagues aware of their diagnosis had meant that people were more supportive at work and certain allowances were made:

Siwan: With a diagnosis, certainly in my case, psychiatrists point me in the direction of help. For example, he put me in contact with the bipolar research network, and I was a participant and I found that very useful, to actually reflect on my situation.

David: So there's the help you get access to, medication, help from other professionals, be it psychologists, you know, CBT, doing CBT, and some people if they need help with benefits and things, you need to have a diagnosis to open those doors.

Jacob: I mean, my work have been really good, they've made allowances for it. It's the law as well, it comes under the disability discrimination act, it's illegal, they can't make you take accountability for your sickness, well they can if it's a cough or a cold or something, but otherwise it's there for your own sake, they can't do that legally. As a company they've confirmed that to me as well.

Stigmatised versus desired

Participants had different views about whether stigma was problematic for people with a diagnosis of bipolar disorder. Whilst some believed it was very much an issue, others speculated over the media portrayal of bipolar and the idea that many celebrities have openly discussed having the disorder, leading to a view that it was a fashionable or desirable diagnosis:

David: The stigma thing, if you're a person who has got a particular mental illness it can be scary to mention it to other people in general.

Jacob: The social stigma has become less now – all these celebrities with it...

Elanor: Yeah, it's become fashionable now ... If they only knew! I don't think there's a stigma attached to it at all now.

David: I think people would want to buy it in pills wouldn't they, you know these pro-plus things you can get ... if you really had to get through a particular sales job or something, you could buy 'bipolar' by the bottle ...

3.1.2 Awareness, knowledge and understanding of bipolar disorder

Participants discussed the fact that awareness and understanding of bipolar disorder differs between different groups and levels of a system (e.g. service users, carers, services and society as a whole) and that those who are often assumed to have some expertise may not in fact be the best informed, and that there may be misunderstandings of the nature of bipolar disorder.

Service users can be experts

Participants were of the view that service users' personal experiences of bipolar disorder mean that they, by default, are well informed about their condition:

Jacob: To a certain extent you're the best one to judge your own condition – say with GPs, if you saw one that didn't know you, they don't know I'm bloody high. They think 'that's just him'.

Siwan: ... medical students in their fourth year do six weeks psychiatry.

David: In it's entirety, so we go along and say I've got 20 years of being a ... (I was going to use a derogatory term!) I think I've got the edge on you with six weeks.

Family members are first to notice problems

All of the participants had had experiences where family members or partners were the first to identify that things were going wrong and encouraged the person to seek help or put plans in place to prevent symptoms escalating:

Elanor: Well, when Dad came over, he said 'listen, I'm not being funny, but we've seen you go really high quickly, we've also seen you go really low quickly, you know yourself that you can't not do anything, when you're feeling like this'.

David: When I had to retire from the police, it was in about 2000 ... my wife arranged for me to go see a psychiatrist. So that was her recognising that they weren't normal swings of behaviour, and that I really wasn't right. And she recognised it. So she did encourage me to go.

Some professionals do not know enough

With regards to services, participants held a view that, whilst knowledge and expertise varied within and between different professions, certain groups, specifically GPs, had inadequate knowledge of bipolar disorder, and this impacted on people's ability to access appropriate help when needed:

David: It would have been nice going back to the GP, if they'd known more mental stuff, I think things would have turned out differently ... This is not slagging off GPs, far from it. But some are awful. Full stop.

Media portrayal is not the reality

In terms of society, all participants felt that whilst the increase in media attention had raised society's awareness of bipolar disorder, the portrayal of the condition is often inaccurate, and that the general public have little idea of what having bipolar disorder is like in reality:

Siwan: Like you say, it seems to be trendy, doesn't it, in certain circles, to have bipolar. Whereas if they realised the reality, they wouldn't go down that road ...

David: People get that glamorous image of hypomania, that it's euphoric, they don't get the other way, when you can go really, really nasty, which is something I detest ...

David: But that lovely image of sort of writing pop songs and launching Virgin Atlantic and numerous things like that, it's not always the real thing.

3.1.3 Issues with the process of assessment and diagnosis

Overall, participants agreed that there were problems with the recognition of bipolar disorder. They broadly agreed with the perspective portrayed in the research literature that delayed diagnosis and misdiagnosis are a problem, and that certain medication could have a detrimental effect on individuals with a bipolar presentation. Three out of four participants had experienced these difficulties first hand.

Delays between symptom onset and diagnosis

Participants considered that signs of bipolar disorder could be present for a long time before they were identified as this:

Jacob: I mean, I think I displayed signs of my illness going back into my teens, but they weren't massively noticeable.

Siwan: Oh yeah, well the depression happened in 1987, then the high, and I wasn't diagnosed with bipolar until 2003. I'd been on venlafaxine for depression. So funny. And I was admitted to hospital.

Misdiagnosis

Participants had all either experienced misdiagnosis before being diagnosed with bipolar disorder or knew someone else who had this experience. Two participants described personal experiences of, in their view, being first misdiagnosed with depression:

Jacob: Um, the misdiagnosis, that doesn't apply to me, but the people I've met through the group, one person was misdiagnosed as being schizophrenic, 20-30 years later he didn't realise he was actually bipolar.

Siwan: Mine was a misdiagnosis. Initially I was diagnosed with depression, and I suppose had I thought about it properly, and had I been asked the appropriate questions by those psychiatrists, I had a high before I became very depressed. But I didn't realise until sometime after. Nobody asked me about it. You're just diagnosed with a depression, then it took many years to actually be diagnosed with bipolar.

David: That mirrors my experience, I had ten years or so of on and off to the doctors typically presenting with depression – questions didn't get asked about anything else you were doing or experiencing.

Unhelpful medication

Some participants had experienced both unhelpful and harmful reactions to antidepressant medication prescribed for what was thought to be depression. One participant described his experience as being so unpleasant that he avoided seeking further help for many years. Another explained how antidepressants triggered a manic episode. Participants also expressed resentment at the overreliance on medication prior to proper assessment:

David: But, certainly, when I presented typically at the doctors it would have been depression that would get noticed and would be like 'here, have some antidepressants'. But my reaction to them was so bad, as in 'shwooooo', that it certainly didn't help with the depression either. I was scared, literally, to go back. But I needed to after several years, because it got, you know, I'm not going to see another Christmas otherwise. Because I had such a bad reaction, to just antidepressants, I got a misdiagnosis, or absence of a diagnosis, if you like.

Siwan: Yes, well I was prescribed with Venlafaxine, 40mg ...

David: I had that once as well – the blue touch paper!

Siwan: Yes, well, after this I had my first major high – then they diagnosed bipolar a few months later.

Elanor: ... then you say 'hang on a minute, let's sit this girl down here and ask a few questions', if you can get me to sit down, and assess again, rather than chucking me full of pills, straightaway. I don't think there's enough assessment over what you're actually doing.

Caution regarding early diagnosis

Whilst participants agreed that not identifying bipolar disorder soon enough was problematic, some participants also expressed reservations about the appropriateness of diagnosing young people with the disorder. It was suggested that during the teenage years people may experience natural variations in mood and that these would need to 'settle' before bipolar disorder could be diagnosed with any conviction:

Siwan: I mean you've got to wait until they're in their 20s.

David: It doesn't settle until ...

Siwan: It doesn't settle, yes.

David: You certainly have to look at treating any really exaggerated symptoms, if someone needs to be sectioned they need to be sectioned, but to rush in, thinking of my daughter, for example, she would tick the boxes of many of the diagnostic criteria, and I think it would be unfair and wrong to label her now.

Siwan: I mean, people who are growing, it's not good at that age, to get a diagnosis, is it?

3.1.4 The impact of bipolar symptoms on seeking and receiving help

Participants thought that there were certain aspects of a bipolar presentation which could affect how and when people seek help. Some symptoms may make people either reluctant to seek help (e.g. not wanting to stop the experience of hypomania or mania) or even unaware that it would be appropriate to do so. Additionally, people may only seek help when specific aspects of bipolar disorder are problematic, meaning that other important symptoms may not be picked up.

Lack of insight

Participants acknowledged that, when experiencing mania or hypomania, people with bipolar disorder may not try to seek help as they may often lack insight into there being anything wrong. It seemed that, with the benefit of hindsight, people were more able to identify and recognise the downsides of manic/hypomanic experience, but that few had this insight in the pre-diagnosis stages of bipolar disorder:

David: And you've just got loads of things, all on the go at the same time. That's where people have this thing about the whole creativity thing, they think they're doing really good. Then you look back on it and you think 'swoosh ...'

Siwan: And maybe, if they're high, but maybe they feel so good they're less likely to access help. So we need to encourage them to access help if they are very high.

Jacob: When I first had a high, I was off the scale. If you had 0 to 100, I was like 98 or something. So I was completely off the scale, originally, and I had no idea.

Distinguishing hypomania from normal experience

Some participants explained that it could be quite difficult for both service users and professionals to differentiate between the experience of normal positive mood and productivity and what would be more appropriately conceptualised as hypomania in the context of bipolar disorder:

David: I never get completely manic, so with people getting hypomanic, it's not always possible to know the distinctions.

David: It's very difficult to differentiate between being, say, highly functioning and, you know, working really well, and professionally you're sort of towards the top end of what you can do, and what is going to make you unwell.

People seek help for depression

Participants were of the view that people would be more likely to seek help for depression, and may not report experiences of mania or hypomania due to not appreciating the possible relevance of these at the time:

Elanor: I agree with ... about the depression side, I think people would go and seek help if you're low, because when I'm on a high, anyway, like I said before, I don't think there's anything wrong, I always think I'm fine.

Fearing consequences of reporting symptoms

Participants speculated that people may also be reluctant to report all of their symptoms due to fear and uncertainty of potential consequences of reporting experiences that may be indicative of more severe mental illness:

David: I think at the moment, judging on our own experience and that of others, I think we'd be a bit worried just going in for an honest 'chat' with someone, or an assessment, for fear that we'd get locked up. On a 28 day thing or some such.

Seeking help for unmanageable symptoms

Participants thought that people would be likely to seek help when symptoms became so severe that people were unable to cope, or when the consequences of symptoms or behaviour had become unmanageable:

Siwan: I guess the severe depression ... Very depressed, they feel so absolutely awful that they want to do something about it.

Jacob: Running out of money, because you spend a lot of money on a high ... you seek help to try and get your money back in order.

3.1.5 Unmet service needs regarding assessment and diagnosis

Participants thought that a number of factors contributed to the inadequate assessment and recognition of bipolar disorder. These unmet needs were mainly considered to be evident in a primary care setting.

Mental health is not taken seriously enough

Participants all thought that mental health issues were sidelined in favour of physical health issues in primary care, and that there was not enough appreciation of how physical and mental health issues could impact on each other:

David: It really needs to be increased in Primary Care. They've separated it [mental health] for way too long from physical illness but the two are just inseparable. And that's just ignoring the fact that many

physical problems will always have a mental aspect afterwards, even if there wasn't one before. So it really needs to have its profile raised with regard to recognition and importance.

Lack of mental health training

Participants considered that those working in primary care, including GPs, are not trained enough on mental health issues, making it harder to effectively assess mental health conditions:

Jacob: The only time they'll see you on the day is in an absolute emergency. And the person who is assessing you, in an emergency, is the receptionist, who's had no qualifications, no anything.

David: My now GP doesn't know what a psychiatrist knows, but he does deal with mental health related things very seriously, to the extent he'll give me three quarters of an hour if he needs to, so that's good, but he still doesn't really know much. So, no, they don't really know much about bipolar disorder and mental health stuff in general. They aren't trained enough about it, I think the importance of it isn't perhaps revealed enough.

David: And this is not me being unpleasantly critical of GPs, they are 'general' practitioners – I spent four days at their annual conference last week and almost without exception, including some of the students, or trainee doctors, they all feel very ignorant as regards to any mental health related things.

Limited resources

Participants acknowledged that primary care practitioners had high caseloads and limited time available to them to spend with each patient, making it harder for them to carry out a detailed assessment:

David: The reality is that they haven't got the time to really go into it, or the knowledge or experience. So they would like to do a lot more, but they can't.

3.1.6 Professionals differ on their approach to mental health

Participants took the view that professionals could differ both within and between specific professions on their knowledge and approach to mental health issues, and that certain professionals had an approach to assessing and working with people with mental health issues that service users preferred.

The skills of medical professionals can vary considerably

With regards to those with a medical training, participants were most critical of GPs, but also acknowledged that some GPs were very good, especially if they were more experienced or had an interest in mental health. Psychiatrists were generally assumed to be knowledgeable on bipolar disorder, but participants also thought that their abilities could vary:

David: But of course doctors, sorry bad doctors, hate being told ... people suggesting what might be wrong with them. A good doctor will want to know. There's not enough of them.

Jacob: The doctor I see, he's the head doctor, he's pretty good on bipolar and depression and stuff as well, so I'm quite lucky to be having him. It depends on the practice, really. When I was in the valleys, some of the GP practices weren't so good.

Jacob: I agree to some extent [about the criticisms levelled at GPs], but my GP was excellent, he diagnosed me before the psychiatrist offered a diagnosis, and I was quite happy with his support.

David: My psychiatrist's very good, but, er, in general I think there's difference within each profession.

Service users can prefer the approach of non-medically trained professionals

Some participants indicated that they can feel more listened to and understood by professionals who are not doctors. They also speculated that people with a different training to medicine may be in a better position to assess and recognise mental health related health symptoms:

Elanor: I went to one of those check-ups that you have to have, and it was with the nurse, and I said 'actually I feel better from spending half an hour with you than I do with the psychiatrist!' I mean perhaps because by their nature and training they listen to what you've got to talk about and what your issues are.

David: Well, I think in general most other professionals know more than GPs, I mean maybe just a typical nurse, for example, or a typical physiotherapist, or a typical occupational therapist, even if they're not a mental health specialist, perhaps because the nature of their work is more touchy feely, it's more caring, perhaps they're more likely to notice.

David: Unfortunately, this kind of thing [assessment] is an art, which you [the facilitator] would be more akin to with your training as a psychologist.

3.1.7 Improving assessment and diagnosis

Participants came up with a number of ideas regarding more effective assessment and recognition of bipolar disorder, and thought that these would also be important things to ask other service users about as part of the online survey.

Being alert to relevant experiences

Participants thought that there were certain features of bipolar disorder, or relevant information, which professionals should be more aware of in order to consider the possibility that a service user might have bipolar disorder. These could be related to particular experiences such as the type of depression, psychotic symptoms, extreme productivity, or a family history of mental health problems.

Elanor: Questions about family histories.

David: Mine has become more and more obvious, the family history thing, because I've gone looking for it. My sister's got a problem, my uncle's got a problem, my mum's 'weird' by her own description, my grandfather gassed himself, and it turned out that two other people in that line also committed suicide. That blood thing, there you go, you know? It's hardly surprising. So it certainly I think is an involved question. And it does seem to happen more often than not.

Asking the right questions

Participants thought that if professionals asked just a few carefully thought out questions, they would soon gain an understanding of whether someone is experiencing bipolar symptoms. They suggested that the most useful lines of enquiry would be to ask people about their mood and corresponding behaviour over a certain time period:

Jacob: They can just ask a couple of questions to ascertain whether you're unipolar or bipolar, it's just the type of question they need to ask, really.

Siwan: Just for them to ask, when someone comes with depression, 'have you ever been high before?' because I don't think that question's being asked at the moment, which is stopping people from being diagnosed.

Elanor: I think if I was on a high, and the GP said to me, 'what did you do yesterday?' and I told him everything I had done on that day I was on a high, I think he would know straight away that that wasn't normal. What time did you go to bed, what time did you get up, did you have your breakfast ... OK, what did you do then? Sometimes I think back to the amount of things you cram in when you're awake, it's unbelievable. And that's not normal.

Elanor: Perhaps if they asked some sort of question like 'when is the last time you felt happy, what were you doing?'

David: That's a great one.

Elanor: You know, a question like that, when you're feeling down you can still remember, and it was like 'oh it was when I went to a wedding and I was shopping for a dress and I went into this shop, that shop, and I bought one that cost 500 pound.' And the GP would go, 'would that normally be what you'd spend on a dress?' You know, and get to it that way.

More training for those working in primary care

As participants identified lack of mental health related training as an unmet need, they considered that more training on mental health problems and bipolar disorder in particular was therefore necessary. They considered that this might improve the assessment and accurate diagnosis of bipolar disorder and help to reduce the possible risk of service users harming themselves:

Siwan: Even the practice nurses need more mental health training, to make them more effective, because they're easier to access than the GP, usually, I think.

David: And it should be happening during training that, you know, when you're running practices, the danger of not dealing initially with a mental health problem effectively results in that person hanging from a tree an hour later, that's very real.

More in-depth assessments

Participants felt that when people present with mental health or mood related symptoms, assessments should be more comprehensive and detailed, and that the assessment process should be allocated more time. Again, it was felt that this was particularly important due to the risks of harm associated with very high or very low mood:

Elanor: I personally think that once you show some kind of high, you should go to hospital, not be pumped straightaway full of tablets, but assessed properly and see how you are behaving in a safe environment.

David: I mean, they can't spend all day with you, obviously, but they could put that little stop watch to the side. To make sure there's a good chance when you walk out that door that you're going to come back tomorrow.

Easier access to mental health trained professionals

Participants thought that if primary care practitioners were not trained on mental health issues, then people with mental health problems should be able to access appropriately trained professionals more easily and preferably in a primary care setting:

David: One GP practice, I've forgotten which one, every Friday they have 'mad day' ... at the very least the CPN will come in, often the clinical psychologist. Every Friday, if there's anything that's vaguely mental health-y, there's someone to see them, in addition to regular bookings, they can just say, 'tell you what, Dr so-and-so is in on Friday, they're really good, do you wanna go see them?' And that would be helpful, if you could get really quick access to something.

Screening questionnaires

One participant suggested that bipolar disorder screening questionnaires could be a useful tool to use in primary care to help GPs to flag up possible bipolar disorder:

David: There are short screening questionnaires they can run through if they're not quite sure ... I was given one by the psychiatrist which was intended to help answer that question for GPs, things they might look for.

Improving communication

Participants considered that more general communication about mental health problems in society would make it easier for people to seek help, as well as facilitate the development of greater general awareness in professionals and the public. Participants also felt that being talked to openly and listened to by professionals made them feel more engaged and valued as a person:

Siwan: Yep that would be nice. Greater overall recognition, just that if people talked about it more, like people would talk about having a headache, they would go to their GP a lot earlier. Then it gets picked up earlier.

Elanor: And when you go see the psychiatrist, you sit there and 'how're you feeling, blah de blah, blah de blah ... Ok, up this, lower that, blah blah blah' and they're gone. Whereas the nurse comes in, sits down, talks about what you've been doing this week ... and properly listens, you know? You appreciate that. You want to be treated like a person.

Asking family and friends

Participants thought that family and friends could be an important, currently under-used resource for gaining an objective view of what an individual may be experiencing, especially if people lack insight into their symptoms. They also emphasised the importance of including carers' views and opinions in the survey:

Jacob: My parents really encouraged me, and my sister encouraged me, to go to the doctor. I don't think they really knew very much about bipolar, but the love they have for you, they pick it up anyway. They could have told you all about what was going on, even if I didn't know myself.

Elanor: Have you put anything in [the survey] about carers? You've asked who we go to for help, and they're often the first port of call ... you need to ask them what they think about it all.

David: It's something that is constantly missed.

3.2 SUMMARY

A thematic analysis of the focus group discussion identified a number of issues relating to the assessment and diagnosis of bipolar disorder from a service user perspective, as well as ideas for possible solutions. Participants considered that particular problems existed with the approach to mental health problems and the recognition of bipolar disorder in primary care specifically. The themes and subthemes identified were aimed to represent issues and ideas that focus group participants discussed as being relevant or important. These were then used to devise questions or parts of questions in the online survey to ensure the representation of service user opinions in the design of the research (see Section 5.1).

Table 3.1 - Summary of themes and subthemes

THEME	SUBTHEME
1. Meaning and implications of a bipolar diagnosis	Empowering versus self-limiting
	Chronic condition
	Making sense of experiences
	Opening doors to support
	Stigmatised versus desired
2. Awareness, knowledge and understanding of bipolar disorder	Service users can be experts
	Family members are first to notice problems
	Some professionals do not know enough
	Media portrayal is not the reality
3. Issues with the process of assessment and diagnosis	Delays between symptom onset and diagnosis
	Misdiagnosis
	Unhelpful medication
	Caution regarding early diagnosis
4. The impact of bipolar symptoms on seeking and receiving help	Lack of insight
	Distinguishing hypomania from normal experience
	People seek help for depression
	Fearing consequences of reporting symptoms
	Seeking help for unmanageable symptoms
5. Unmet service needs affecting assessment and diagnosis	Mental health is not taken seriously enough
	Lack of mental health training
	Limited resources
6. Professionals differ on their approach to mental health	The skills of medical professionals can vary considerably
	Service users can prefer the approach of non-medically trained professionals

Table 3.1 continued - Summary of themes and subthemes

THEME	SUBTHEME
7. Improving assessment and diagnosis	Being alert to relevant experiences
	Asking the right questions
	More training for those working in primary care
	More in-depth assessments
	Easier access to mental health trained professionals
	Screening questionnaires
	Improving communication
	Asking family and friends

CHAPTER 4 – RESULTS: SURVEY

4.0 OVERVIEW

A total of 327 people completed the survey. Of these, 262 were service users, and 65 were carers. An accurate response rate cannot be determined, as although the publicity email was sent out to just over 2000 Bipolar UK members, it is not known how many people may have had access to this email or been made aware of the web-link via other publicity material. All participants consented to taking part in the study by responding positively to the four consent statements the beginning of the survey. Unless otherwise specified, results reported are from the service user version of the survey. Responses from the carers' survey will also be summarised where relevant. Some question and response option wording will be summarised for the purposes of brevity (e.g. in tables/diagrams) in this report. See Appendix C for complete survey questions and contents, which will be referred to throughout this chapter as indicated by references to question numbers (Q).

4.1 DEMOGRAPHIC CHARACTERISTICS

4.1.1 General demographics

Survey respondents comprised of 67.6% females and 32.4% males. Ages ranged from 20 to 83 years (mean = 47.3, sd = 12). The majority of respondents were in paid employment (43.9%), a further 19.4% were in unpaid work, 16.4% were unemployed and 20.2% retired. Regarding relationship status, 43.9% respondents were married, 10.8% were divorced or separated, and 34.3% were single. The majority of participants (79.1%) described their ethnicity as white British. (Table 4.1/Q2 – 6).

Of those who completed the carers' survey, 58.5% were female and 41.5% were male. Their mean age was 57.9 years (sd = 11.9), ranging between the ages of 23 and 82 years. Most were either retired (46.2%) or in paid employment (41.5%). The majority (72.3%) were married. Regarding ethnicity, 90.8% described themselves as White British (Table 4.1).

Table 4.1 Demographic characteristics of survey respondents

SERVICE USERS		CARERS	
Variable	% (N = 262)	Variable	% (N = 65)
Gender		Gender	
Male	32.4	Male	41.5
Female	67.6	Female	58.5
Age (Mean = 47.3) (St Dev = 12.0)		Age (Mean = 57.9) (St Dev = 11.9)	
20-29	8	20-29	3.1
30-39	19.8	30-39	4.6
40-49	28.2	40-49	13.8
50-59	27.1	50-59	27.7
60-69	14.9	60-69	33.8
70+	1.9	70+	16.9
Employment status		Employment status	
Paid employment	43.9	Paid employment	41.5
<i>(Full-time</i>	21)	<i>(Full-time</i>	16.9)
<i>(Part-time</i>	16)	<i>(Part-time</i>	12.3)
<i>(Self-employed</i>	6.9)	<i>(Self-employed</i>	12.3)
Unpaid work	19.4	Unpaid work	7.7
<i>(Voluntary work</i>	9.5)	<i>(Voluntary work</i>	1.5)
<i>(Student</i>	4.6)	<i>(Student</i>	0)
<i>(Housewife/husband</i>	5.3)	<i>(Housewife/husband</i>	6.2)
Not in work	36.6	Not in work	50.8
<i>(Unemployed</i>	16.4)	<i>(Unemployed</i>	4.6)
<i>(Retired</i>	20.2)	<i>(Retired</i>	46.2)
Relationship status		Relationship status	
Married	43.9	Married	72.3
Cohabiting	8.4	Cohabiting	4.6
Separated/divorced	10.8	Separated/divorced	7.7
Widowed	1.5	Widowed	6.2
Single/dating	34.3	Single/dating	9.2
Ethnicity		Ethnicity	
White British	79.1	White British	90.8
<i>(English</i>	67.1)	<i>(English</i>	73.8)
<i>(Scottish</i>	3.1)	<i>(Scottish</i>	6.2)
<i>(Welsh</i>	5.7)	<i>(Welsh</i>	7.7)
<i>(Other White British</i>	3.1)	<i>(Other White British</i>	3.1)
White Irish	1.9	White Irish	0
White Other	11.8	White Other	3.1
Any Mixed	3.1	Any Mixed	0
Any Asian	0.8	Any Asian	3.1
Any Black	1.1	Any Black	1.5
Any Other	2.3	Any Other	1.5

4.1.2 Access to healthcare

Survey respondents were most likely to access healthcare in the UK or Ireland (88.2%) although 8.8% accessed services in North America (Fig 4.1/Q7). Of those who accessed healthcare in the UK or Ireland (N=231) the majority (84%) were based in England (Fig 4.2).

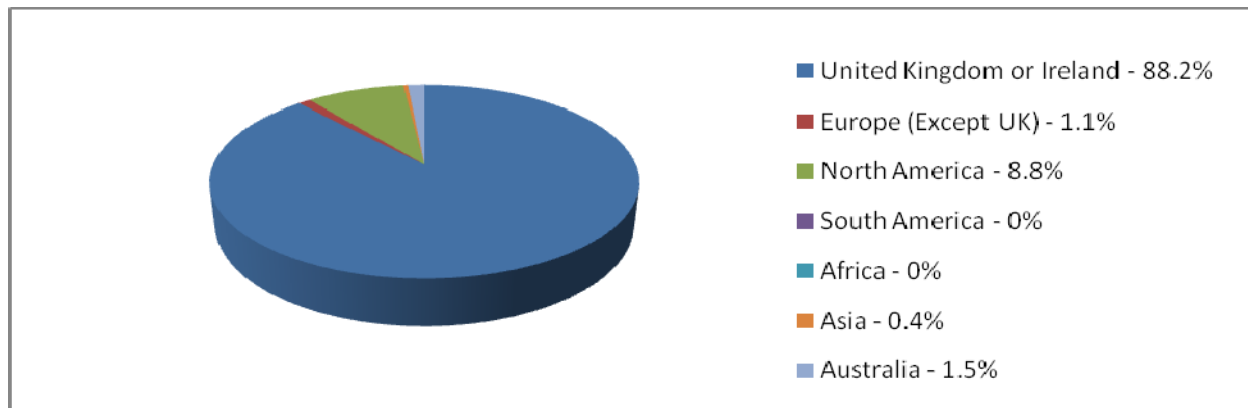


Figure 4.1 Percentage of respondents accessing healthcare by continent

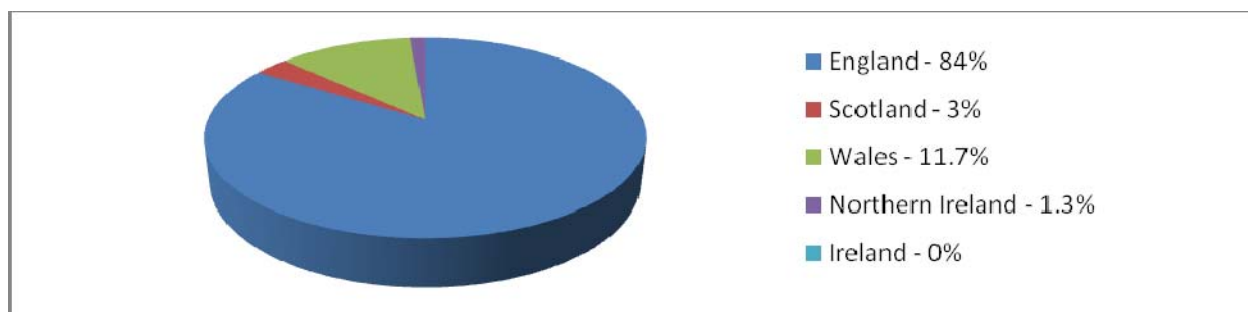


Figure 4.2 Percentage of UK based respondents accessing healthcare in each country

Figures for carers were similar, with 93.8% accessing services in the UK (N=61), and 91.8% of these being based in England.

4.1.3 Type of diagnosis

Respondents were asked three questions (See Q8) about their experiences of bipolar symptoms/episodes which mapped on to DSM-IV diagnostic criteria for bipolar I, bipolar II and bipolar NOS in order to validate self-reported diagnosis and to indicate the type of bipolar disorder participants were experiencing. This format was chosen because some focus group

participants indicated that they had not been told whether they had bipolar I, bipolar II, or 'just bipolar'. Of all respondents, 81.3% (213 people) had had experiences which would be consistent with a diagnosis of bipolar I, 14.1% (37 people) indicated that they had experiences more similar to a diagnosis of bipolar II. The remaining 12 people (4.6%) were most likely to meet criteria for a diagnosis of bipolar NOS.

4.1.4 Carer relationship

Carers all reported knowing the person with bipolar disorder for between 5 and 50 years, and 20% had known them all their life. Most carers (90.8%) had known the person they cared for before they were diagnosed with bipolar disorder.

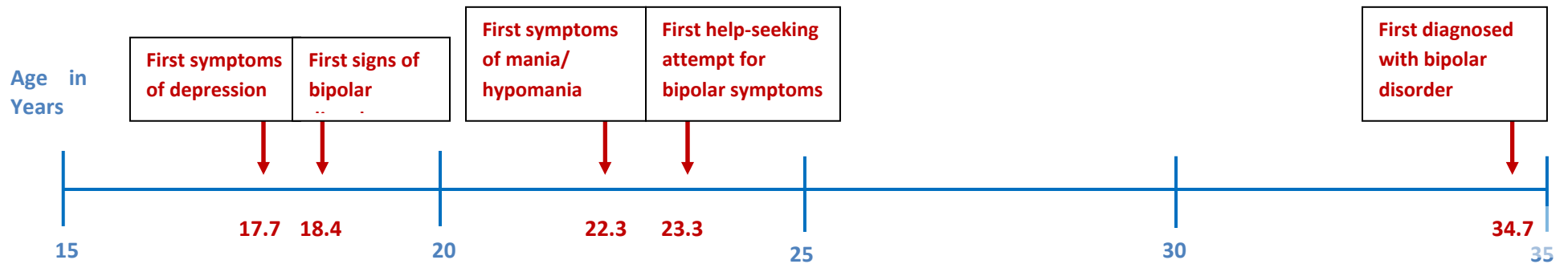
4.2 EXPERIENCE LEADING UP TO DIAGNOSIS

4.2.1 Age at key milestones

Respondents were asked a number of questions about when they first experienced bipolar or mood related symptoms (See Q9 -13). They were asked to give their best estimate of how old they were when they a) first showed any signs of having bipolar disorder b) first experienced symptoms of depression c) first experienced symptoms of hypomania or mania d) first sought help for symptoms of bipolar disorder and e) were first diagnosed with bipolar disorder (see Table 4.2). Participants first experienced symptoms of depression at a mean age of 17.7 years, then first signs of bipolar disorder were experienced at a mean of 18.4 years. First experience of manic or hypomanic symptoms occurred at a mean of 22.3 years. People first attempted to seek help for their bipolar experiences at age 23.3 years, but did not receive a diagnosis of bipolar disorder until a mean of 34.7 years, over 11 years after help was first sought for it (See Fig 4.3) and over 15 years after first signs of bipolar disorder were experienced.

Carer responses to these questions showed a fairly similar pattern, although they thought that first signs and help-seeking happened a few years later and diagnosis occurred a couple of years earlier than service users themselves thought. However, carers' estimations still indicate that service users experienced a delay of over six years between help-seeking and diagnosis (Table 4.2).

Figure 4.3 Timeline showing the mean age in years of first symptoms, first help-seeking and first diagnosis of bipolar disorder for 262 service user respondents



Variable (In years)	SERVICE USERS			CARERS		
	N*	Mean	St Dev	N**	Mean	St Dev
a) Age first signs of bipolar	262	18.4	9.7	61	23.3	11.4
b) Age when first experienced depression	256	17.7	8.9	58	21.2	9.9
c) Age when first experienced mania/hypomania	262	22.3	10.6	62	25.3	18
d) Age when first sought help for bipolar symptoms	248	23.3	9.2	60	26.2	19
e) Age when first diagnosed with bipolar disorder	262	34.7	10.3	64	32.8	30

Table 4.2 Mean age in years of participants at different illness milestones from both service users' and carers' perspectives

NB: Respondents could choose any specific age between 6 and 100. '5 or under' was also included as an option, as it was thought that respondents were unlikely to experience symptoms younger than this, or to be able to remember exact ages when under 5 years of age. However, a number of participants selected the '5 or under' option for a) – d). For the purposes of analysis, this was scored as '5'.

* Some respondents indicated that they had not experienced depression prior to diagnosis, or did not seek help prior to diagnosis, hence Ns lower than the total of 262 for b) and d) as these people were excluded from the calculation.

** As well as 'not applicable', carers also had the option to answer 'don't know' to these questions, hence the Ns are lower than the total of 65, as these people were excluded from the calculation.

4.2.2 Aspects of bipolar disorder experienced at different stages

4.2.2.1 Type of first experience

Participants were asked what they considered their first signs of bipolar disorder to be most similar to (Fig 4.4/Q9a). The highest number of people (39.3%) reported the first sign of bipolar disorder to be similar to depression, closely followed by a further 38.5% indicating that the experience of variable moods was the first sign for them, meaning that a total of 77.8% of people's first experiences of bipolar were most similar to depressed or mixed mood states, rather than the mania which is typically associated with bipolar disorder.

Of the 8 (3.1%) people who responded to this question with 'other', five (1.9%) reported anxiety, two (0.8%) reported psychosis and one (0.4%) indicated that their first signs resembled autism-like features as a child.

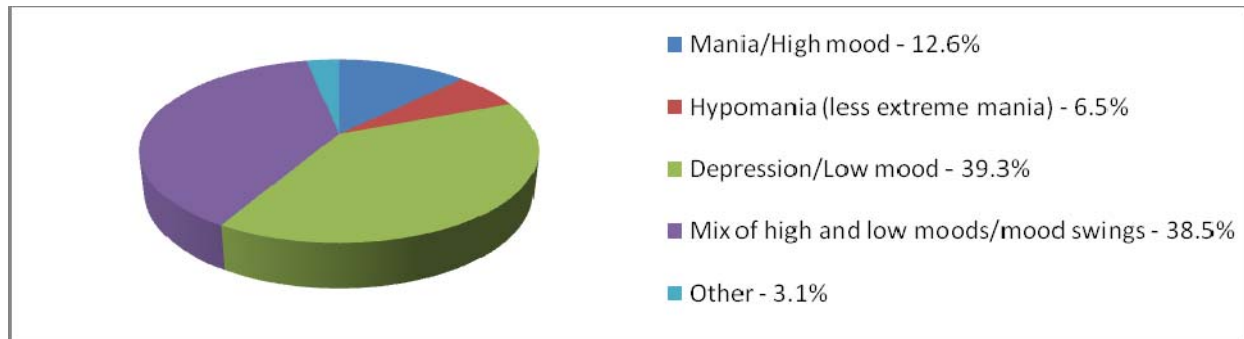


Figure 4.4 Percentage of respondents experiencing different types of early signs of bipolar disorder

Carers also agreed that depression was the most frequently occurring first sign, with mixed moods being the second most likely.

4.2.2.2 Type of experience when help sought

Participants were asked what aspects of bipolar disorder they were experiencing when they first sought help (Fig 4.5/Q12b). The majority (59.5%) indicated that they were depressed at the time.

Of the 25 people (9.5%) who responded with 'Other', 12 (4.6%) suggested that they sought help for anxiety, five (1.9%) for psychotic experiences, one (0.4%) following a suicide attempt and one (0.4%) for 'circadian rhythm disorder'. Six people (2.3%) reported that they had not tried to get help.

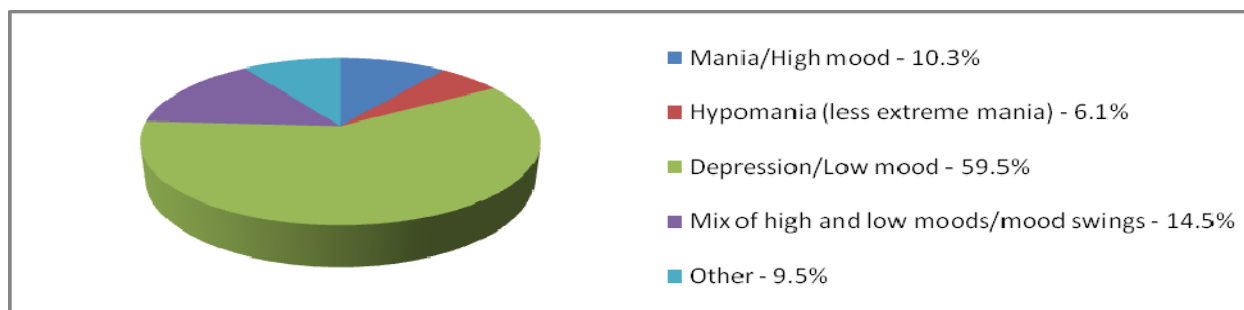


Figure 4.5 Percentage of respondents experiencing each aspect of bipolar disorder when they first sought help

The majority of carers also thought that the service users they knew were experiencing depression when they tried to seek help.

4.2.2.3 Type of experience when diagnosed

Participants were asked what aspect of bipolar disorder they were experiencing when they were first diagnosed with it (Fig 4.6/Q13a). People were most likely to be experiencing mixed moods at the time of diagnosis (32.8%), and second most likely to be experiencing mania (27.2%).

Of the nine (3.4%) other responses, five people (1.9%) reported a 'nervous breakdown' at the time of diagnosis, two (0.8%) reported psychosis, and two (0.8%) indicated not experiencing any symptoms at the time they were diagnosed.

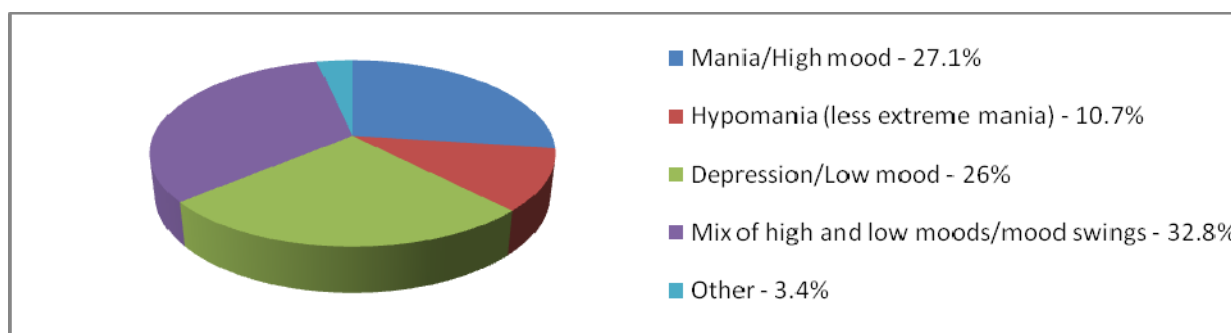


Figure 4.6 Percentage of respondents experiencing each aspect of bipolar disorder when first diagnosed

Carers also thought that the service users they knew were most likely to be experiencing mixed moods when they were diagnosed, with mania being the second most likely symptom at this time.

4.2.3 Help-seeking and response

4.2.3.1 Target of help-seeking

Respondents were asked who they first sought help from for bipolar symptoms prior to diagnosis (Fig 4.7/Q12a). Most people went to a medical professional, with 59.9% first seeking help from a GP, and 9.9% seeking help from a psychiatrist.

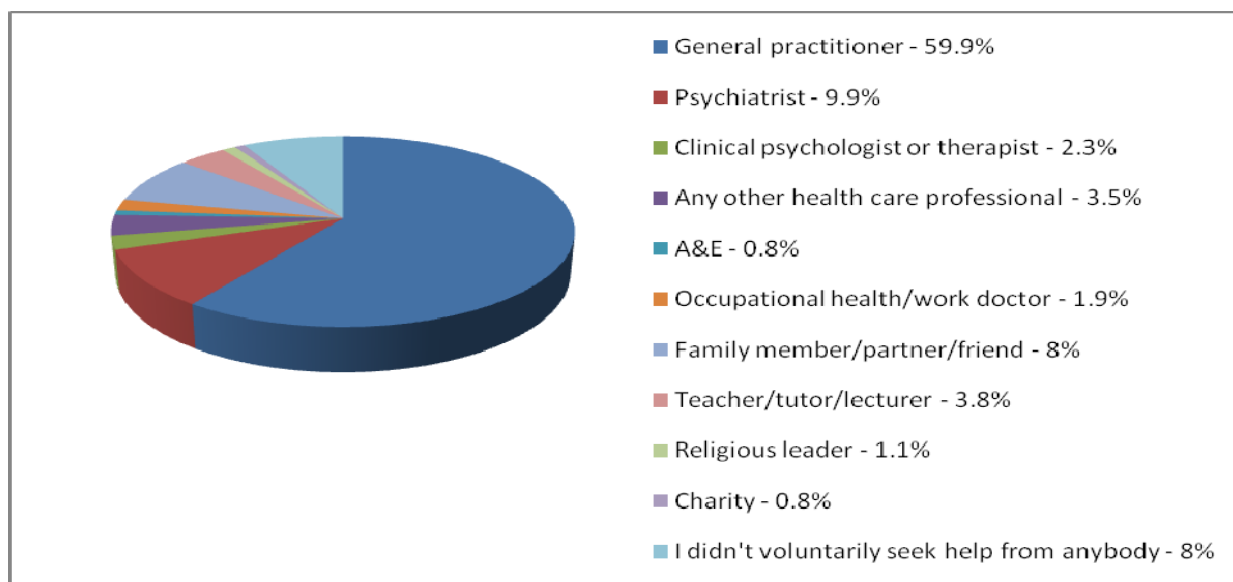


Figure 4.7 First targets of help-seeking by percentage

The vast majority of carers also indicated that the service users they knew had first sought help from their GP.

4.2.3.2 Mechanisms of help-seeking

Respondents were asked to identify the factors that had led to them eventually seeking or receiving help for bipolar disorder (Fig 4.8/Q12c). The 262 respondents were asked to select all possible responses that applied to them. There were 690 answers selected altogether, meaning that participants chose a mean of 2.6 responses each.

'Unmanageable symptoms' was considered to influence help-seeking by the highest number of participants, with 151 people (57.6% of the sample) selecting this as a factor. 'Disturbed sleep' and the suggestion to seek help by family or friends were the next most influential factors, with 111 (42.4%) and 102 (38.9%) people respectively selecting these responses. Risk of harm to self was a consideration for 82 (31.3%) people, and having already attempted suicide prompted 48 (18.3%) of people to seek help.

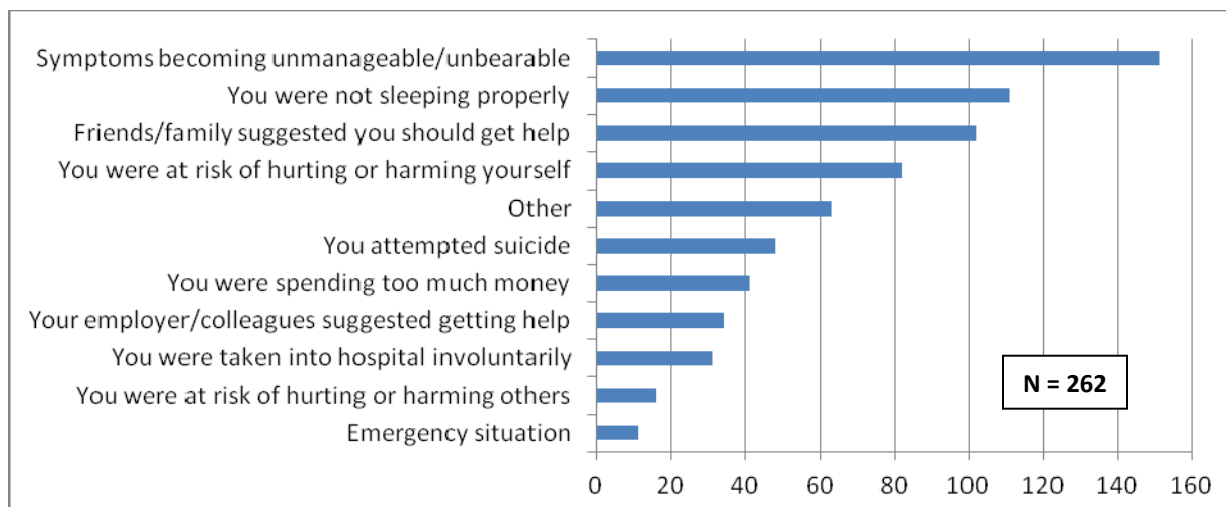


Figure 4.8 Number of respondents considering each factor as influencing first seeking or receiving help for bipolar symptoms

Of the 63 (24%) people who selected 'Other', key themes included voluntary hospital admission as influencing first help received for bipolar disorder. People also elaborated on the idea of symptoms becoming unmanageable as a factor in help-seeking, such as being unable to cope with life events, struggling with excessive drinking/drugs, over/under eating and problems managing relationships. Some people reported that their bipolar disorder was identified by a healthcare or other professional in a routine appointment for something else which led to the receipt of help. Others sought help after carrying out their own research on the internet, in books or seeing a TV programme. A number of people also suggested that 'antidepressants being unhelpful' was a factor that led them to seek help for bipolar disorder.

Carers selected the same three top reasons for help-seeking but in a different order. 'Family and friends suggesting they should get help' was the highest rated, followed by disrupted sleep and symptoms becoming unmanageable.

4.2.3.3 Number of consultations

Participants were asked how many times they had consulted a doctor (any type) specifically with bipolar symptoms before being diagnosed with bipolar disorder (Q13c). Response options ranged between 0 and 20, with an additional option for 'over 20'. It was not expected that many respondents would have consulted someone over 20 times from the focus group discussion, or that, if they had, they would be able to remember the exact number accurately, hence 'Over 20'

was provided as a single option. However, notably, almost one third of respondents (29.4% - 77 people) indicated that they had consulted a doctor over 20 times before being diagnosed with bipolar disorder. The mean number of consultations across all participants was calculated by coding 'Over 20' as '21'. On this basis, the mean number of times people had consulted a doctor before being diagnosed was 10.1 times (sd = 8). However, this is likely to be a conservative estimate, as, if given the option, those who consulted over 20 times may well have selected a figure greater than 21.

A number of carers (23.1%) also thought that the person that they care for had consulted a doctor over 20 times before being diagnosed with bipolar disorder. The mean number of consultations from a carers' point of view, calculated on the same basis as described above, was 9.6 (sd = 7.9).

4.2.3.4 Professional responsible for diagnosis of bipolar disorder

Participants were asked who had first diagnosed them as having bipolar disorder (Fig 4.9/Q13b). Although some were diagnosed by a GP (10.7%), the vast majority were diagnosed by a psychiatrist (86.3%).

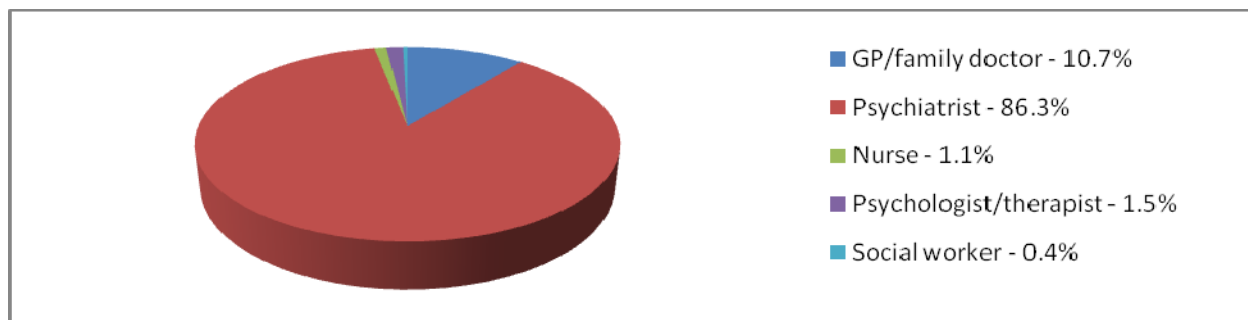


Figure 4.9 Percentage of respondents diagnosed with bipolar disorder by each type of professional

A very similar majority (86.2%) of carers indicated that the person that they cared for was diagnosed by a psychiatrist.

4.3 PROBLEMS WITH THE DIAGNOSTIC PROCESS

4.3.1 Delayed diagnosis

Respondents were asked if they thought that they should have been diagnosed with bipolar disorder sooner than they were (Fig 4.10/Q14). The vast majority (80.1%) thought that their diagnosis was delayed, and that they should have received a diagnosis of bipolar disorder earlier.

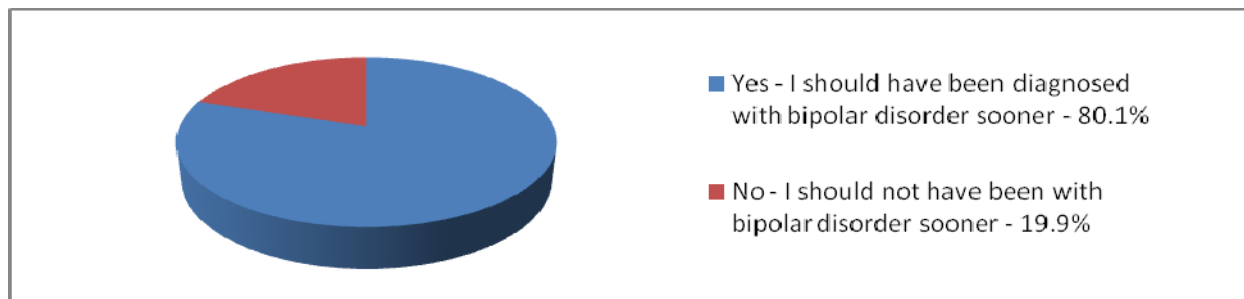


Figure 4.10 Percentage of respondents who thought that they should have been diagnosed with bipolar disorder sooner

The majority of carers (63.1%) indicated that they thought the person they cared for should have been diagnosed sooner than they were. An additional 12.3% were unsure, whilst 24.6% thought that they should not have been diagnosed sooner.

4.3.2 Barriers to diagnosis

Respondents were asked to select from a list of options all the things which they thought had been a barrier to their bipolar disorder being identified sooner (Fig 4.11/Q14a). The 262 participants selected a total of 1040 responses, a mean of four possible barriers to diagnosis identified each. The highest number of participants considered their own lack of insight when experiencing mania/hypomania to be a barrier to them being diagnosed. This applied to 130 people (49.6% of respondents). The second most frequently chosen barrier was having been misdiagnosed/diagnosed with the wrong disorder (115 people - 43.9%). The next three most frequent selections related to GPs, with 97 (37%) people considering that GPs did not know enough about bipolar disorder, 97 (37%) people indicating that GPs did not ask the most useful questions and 78 (29.8%) people suggesting that GPs' lack of sufficient time to assess people properly was a barrier to diagnosis.

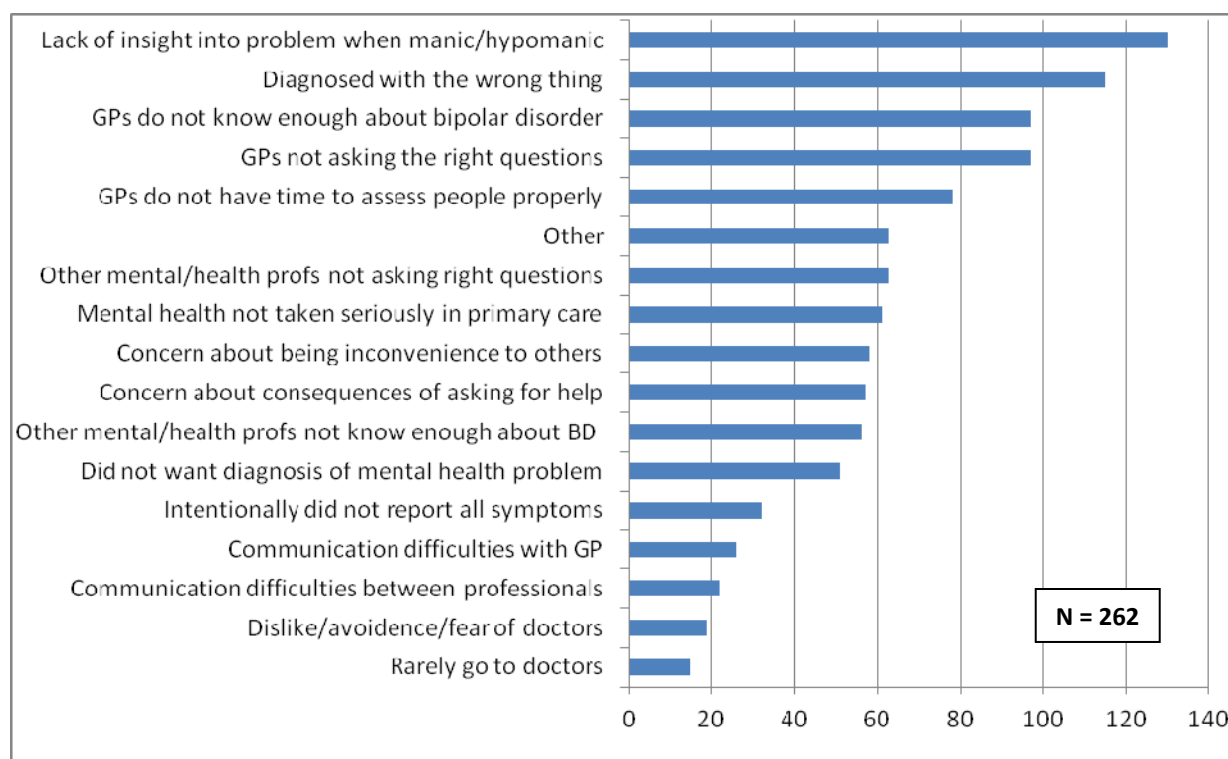


Figure 4.11 Number of respondents considering each factor to be a barrier to diagnosis

Of the 63 'Other' responses, a number of themes were identified or elaborated on. Many people had a negative view of how their problems had been dealt with by GPs. A number of people had experienced GPs not listening or not taking them seriously. People indicated that if a patient is unknown to a GP this makes it difficult to identify a problem. Other people thought that comorbidity with other conditions, such as ADHD, or drug or alcohol abuse, could contribute to professionals not assessing for bipolar disorder. Some people commented that although people are aware of the manic side of bipolar disorder, a less typical presentation, including mixed states or psychosis, had made the diagnosis more difficult because professionals did not know about these features. Others felt that the overlap between bipolar symptoms and 'teenage angst' meant that bipolar was missed by doctors when people were teenagers. Many people were also concerned about judgement and acceptance by others and the stigma associated with mental health problems.

The three most frequently reported barriers from a carer's point of view were very similar to those reported by service users. Lack of insight was most frequently selected, followed by GPs not knowing enough about bipolar disorder, and thirdly, the fact that the service user they knew had been initially diagnosed with the wrong disorder.

4.3.3 Misdiagnosis

Participants were asked if they considered that they had ever been misdiagnosed with something else prior to be diagnosed with bipolar disorder (Fig 4.12/Q15). Over three quarters of respondents (75.5%) thought that they had been previously misdiagnosed.

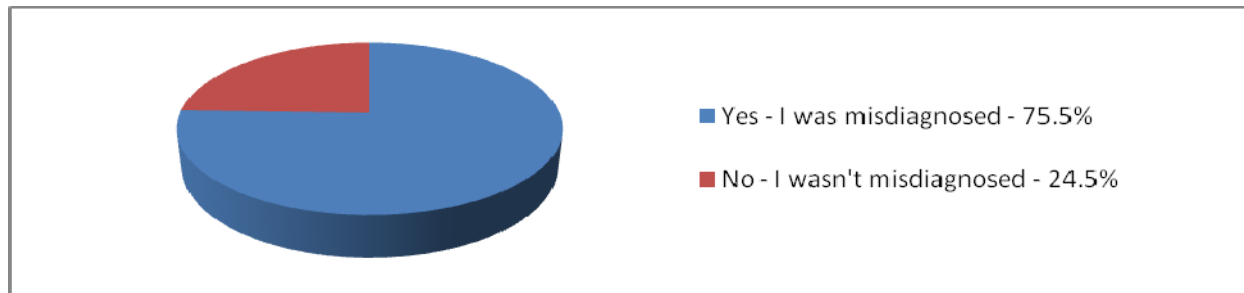


Figure 4.12 Percentage of respondents indicating a previous misdiagnosis

Carers also most frequently reported that the person they cared for had been previously misdiagnosed, but the percentage who believed this (47.7%) was lower than for service users. A further 38.5% of carers thought that the individual they knew had not been misdiagnosed, and 13.8% were unsure.

4.3.3.1 Frequency of misdiagnosis

People who indicated that they had been misdiagnosed (197 people) were asked how many times that this had happened (Q15a). Available responses were any whole number between 1 and 10, with an additional option to select 'over 10'. This was provided as the maximum response as it was not expected that many people would have been misdiagnosed over 10 times. However, 27 people (10.3% of the whole sample and 13.7% of those who had had at least one misdiagnosis) indicated that they had been misdiagnosed over 10 times before being diagnosed with bipolar disorder. A mean figure for the average number of misdiagnoses out of the 197 who indicated that they had been misdiagnosed at least once was calculated by coding 'Over 10' as '11'. On this basis, the mean number of misdiagnoses people had received was 4.3 (sd = 3.4). However, as with Section 4.2.3.3, this is likely to be the most conservative estimate. If those who were not misdiagnosed were included in the calculation (with these people being coded as 0s) the mean number of misdiagnoses across all 262 service user respondents was 2.8 (sd = 3.4) per person.

Of carers who thought that the service user they knew had been misdiagnosed, 16.7% thought that this had happened over 10 times. The mean number of times misdiagnosed reported by carers was 4.1 (sd = 4), similar to the number reported by service users.

4.3.3.2 Type of misdiagnosis

Respondents who had been misdiagnosed were asked what they had previously been diagnosed with (Fig 4.13/Q15b). People could select all predefined answers which applied to them, as well as elaborate in an 'Other' category. The 60 responses in the 'Other' category were coded into additional categories. The 197 people who had received at least one misdiagnosis selected a total of 388 responses to this question, indicating a mean of 2 misdiagnoses before being diagnosed with bipolar. Although this number is less than the mean suggested by the responses to Q15a (4.3) it may be that people did not choose to select or write down in the free-text box all other specific misdiagnoses that they had received. On the other hand, in Q15a, people may have counted all instances of being misdiagnosed, and on multiple occasions the same wrong diagnosis may have been upheld. Of the 197 people who had received at least one misdiagnosis, 182 (92.4% of those misdiagnosed) indicated that one of their misdiagnoses had been depression, which was by far the most frequently reported misdiagnosis. The next most common was an anxiety disorder, with 64 people (32.5%) having been misdiagnosed with some kind of anxiety. The third most frequently occurring misdiagnosis was borderline personality disorder, with 33 people (16.8%) previously having been given this diagnosis.

Overall, 69.5% of the whole sample reported being misdiagnosed with depression. Carers also reported depression to be by far the most common misdiagnosis, followed by an anxiety disorder.

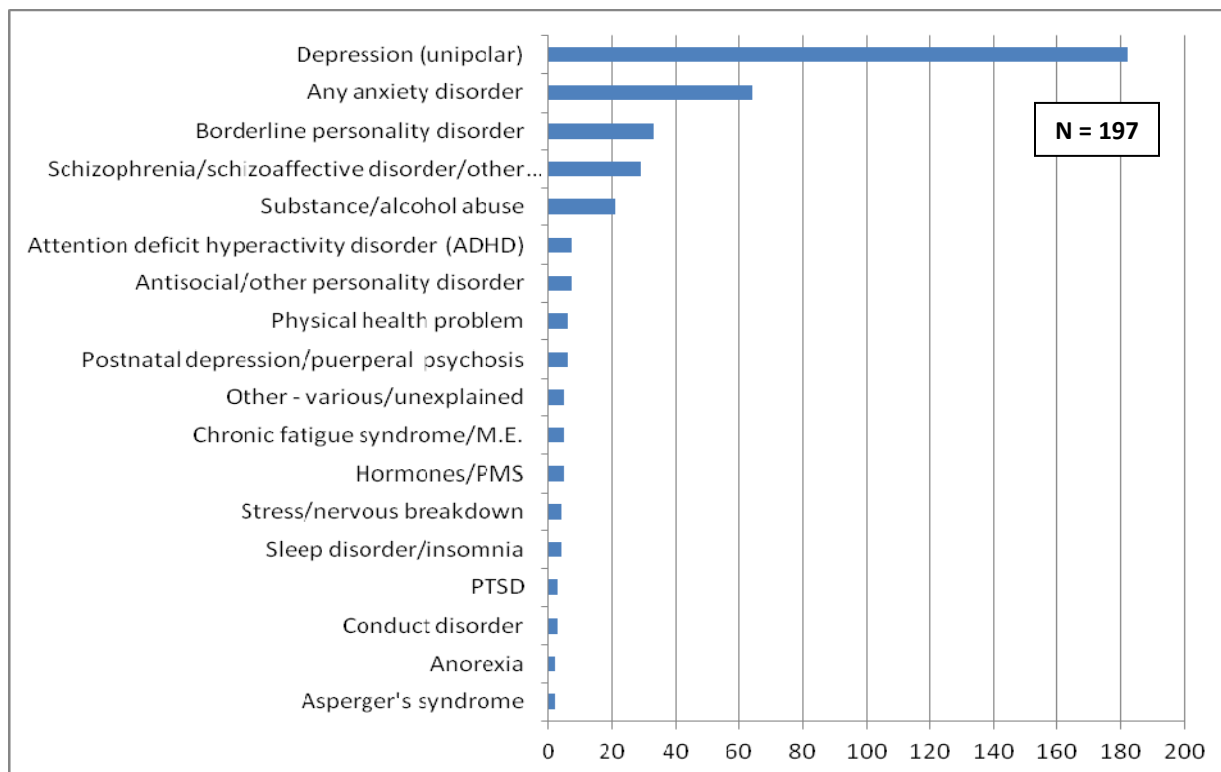


Figure 4.13 Number of respondents receiving each diagnosis prior to being diagnosed with bipolar disorder

4.3.3.3 Antidepressant use

Participants who had previously been misdiagnosed were asked three questions about their experience of antidepressant use (Q15c-e). Of the 197 people who indicated that they had been misdiagnosed, 186 (95.9% of 197) reported being prescribed antidepressants. Of these people, 137 (73.7% of 186) indicated that they had experienced mania/hypomania whilst taking antidepressants, and 43 people (31.4% of 137) indicated that this was their first episode of mania/hypomania. Of all 262 respondents, over half (52.3%) indicated that they had experienced mania/hypomania whilst they were taking antidepressants, prior to being diagnosed with bipolar disorder. For 16.4% of the whole sample, their first episode of mania/hypomania occurred whilst taking this medication.

Similar numbers were reported by carers, with the vast majority of service users who were diagnosed with depression being prescribed antidepressants, and many of those experiencing hypomania or mania whilst taking them. However, as with the service user responses, this was less frequently reported to be the first episode.

4.4 PRE-DIAGNOSIS INDICATORS

4.4.1 Warning signs for mania/hypomania

Participants were asked about their experience of what may have been pre-diagnosis early warning signs for mania or hypomania (Fig 4.14/Q18). They were asked to select the signs that they thought had been most significant to them from a list of possible experiences linked to bipolar disorder in the research literature and suggested by the focus group. People were also able to select 'Other' and to include their own ideas of what may have been pre-diagnosis indicators. The 262 participants selected a total of 2058 responses, a mean of 7.6 possible early warning signs each. The most frequently indicated warning sign selected by 196 people (74.8% of the sample) was disturbed or significantly reduced sleep. 'Racing thoughts' was the second most frequently chosen (161 people, 61.5% of the sample). Over 50% of people indicated a range of other responses, including having many ideas/feeling more creative (157 people), increased productivity (146 people), making ambitious plans (135 people) and increased sociability (134 people). Twelve people (4.6%) reported not noticing any early warning signs, and 33 people (12.6%) reported 'Other' early warning signs in a free text box. Additional warning signs or indicators of mania/hypomania reported were: sensitivity to noise, physical aches and pains before episodes, a belief that one is 'all-powerful', elation for no explainable reason, sensation seeking, excessive exercise and excessive internet dating.

Sleep disturbance was also the warning sign most frequently reported by carers, followed by a tendency to make ambitious plans and increased irritability/argumentativeness.

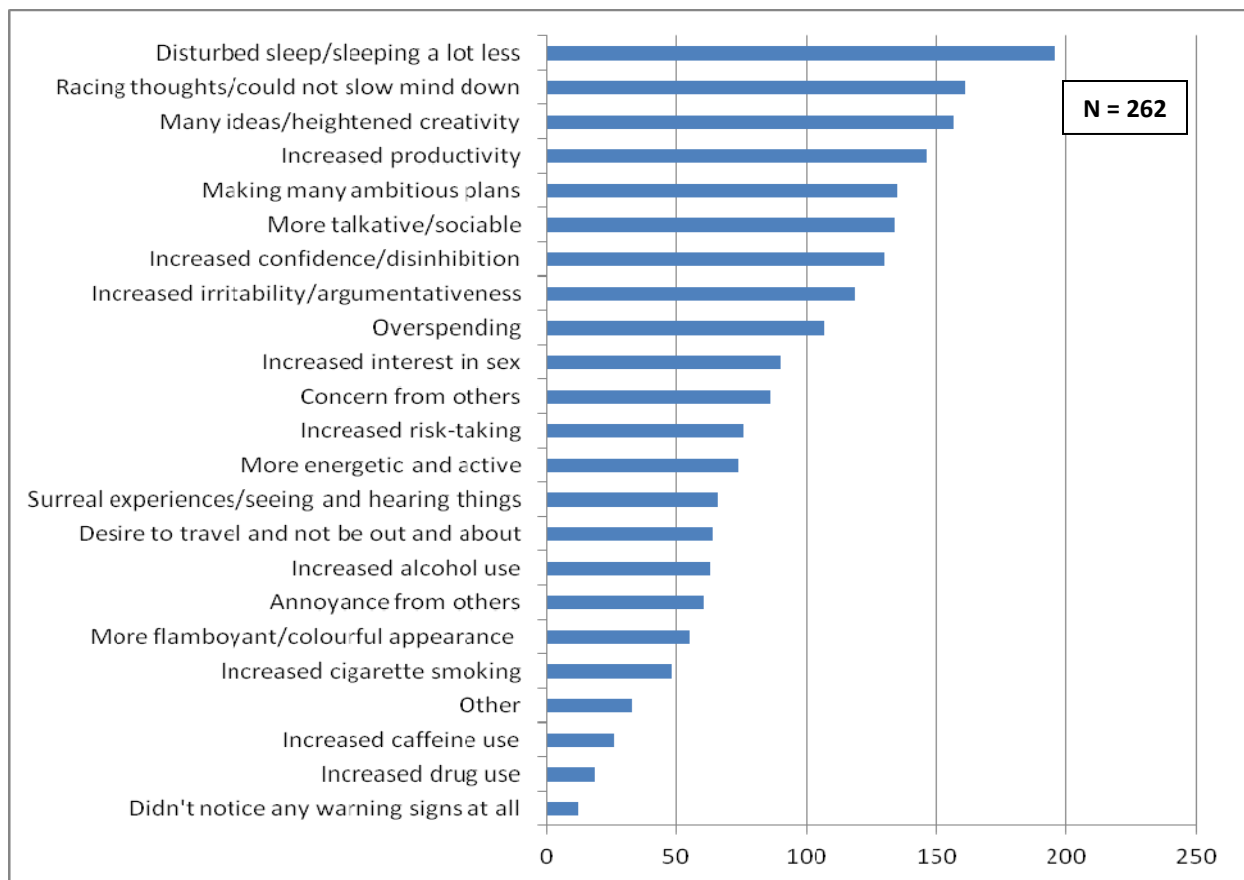


Figure 4.14 Number of participants considering each symptomatic experience as a pre-diagnostic 'warning-sign'.

4.4.2 Pre-diagnosis features of depression

Participants were asked about their experience of certain atypical features of depression prior to being diagnosed with bipolar disorder (Fig 4.15/Q19). These features had been identified in the research literature or by the focus group to be particularly characteristic of bipolar depression and so may serve as useful identifiers of bipolar disorder in those presenting with what may appear to be unipolar depression. Survey respondents were asked to select 'all options that apply', and chose a total of 1576 responses, a mean of six each. The most frequently reported symptom of depression prior to being diagnosed was lethargy/exhaustion, with 190 people (72.5% of the sample) indicating that they had experienced this. Severe, intense and debilitating depression was reported by 182 people (69.5%), and suicidal ideation or attempts by 171 people (65.3%). Only 12 people (4.6%) had not experienced depression prior to diagnosis, and one person (0.4%) reported not experiencing any of these features when they were depressed.

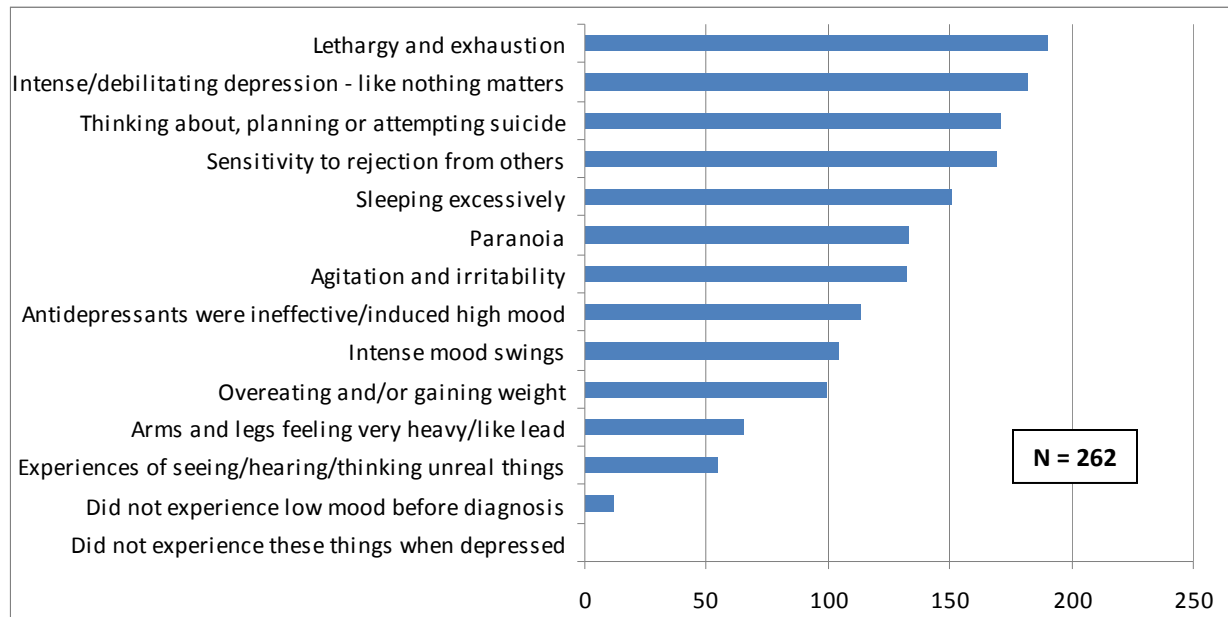


Figure 4.15 Number of respondents experiencing each feature of depression prior to being diagnosed with bipolar disorder

Rejection sensitivity was most likely to be reported as a feature of depression by carers, followed by lethargy/exhaustion and sleeping excessively.

4.4.3 Lifetime risk factors

Participants were asked to select all that applied to them from a list of factors which, according to the research literature and focus group discussions, could put people at risk for developing bipolar disorder (Fig 4.16/Q20). There were a total of 1284 responses, indicating that people had experienced a mean of 4.9 factors. The most commonly experienced risk factor was the occurrence of difficult life events, which affected 200 participants (76.3% of the sample). People were next most likely to have experienced a history of mental health problems in their family, with 165 people (63%) indicating that this was the case. A further 142 people (54.2%) indicated that someone in their immediate family (parents and siblings) had experienced depression specifically, and 62 people (23.7%) indicated that one or more of their immediate relatives had been diagnosed with bipolar disorder. Four people (1.5%) had not experienced any of the listed risk factors.

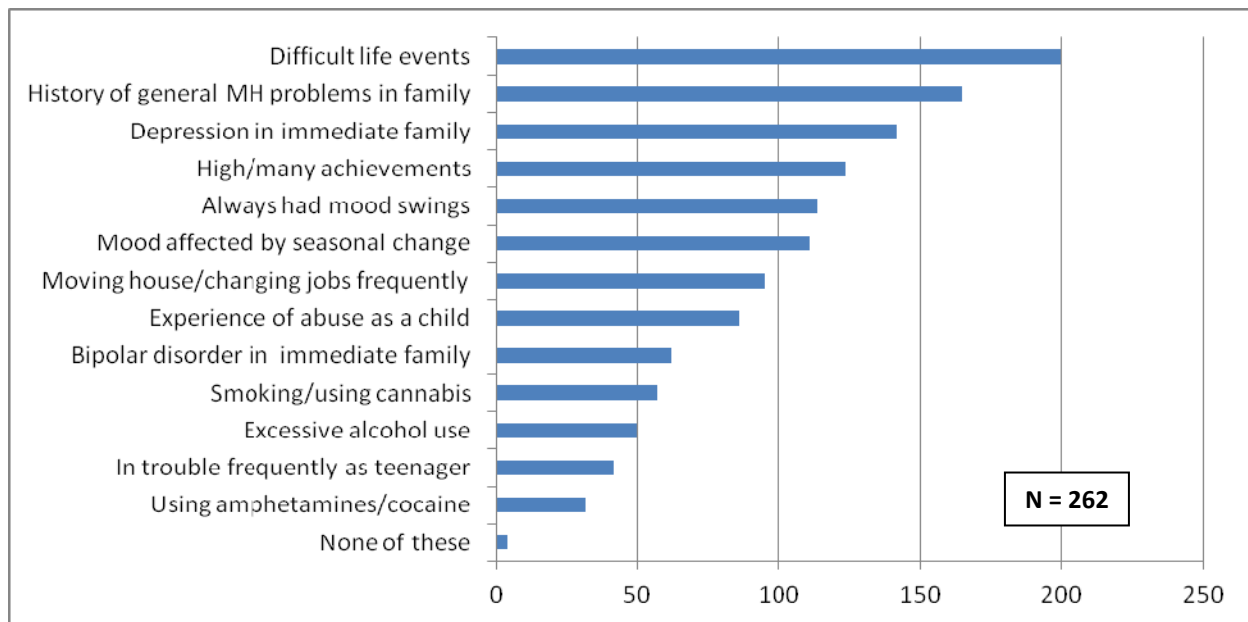


Figure 4.16 Number of participants experiencing each lifetime risk factor

Carers also most frequently reported the occurrence of stressful life events and family links to mental health problems/mood disorders.

4.5 VIEWS ON SERVICES AND IMPROVEMENTS

4.5.1 Understanding of bipolar disorder

Respondents were asked how well they thought that different professionals, service users, carers and society in general understood bipolar disorder (Fig 4.17/Q16). They were asked to rate understanding on a 1 to 10 scale, with 1 representing 'no understanding at all', and 10 representing 'complete understanding'. The mean rating of level of understanding for each group is shown in Figure 4.19. Respondents thought that people diagnosed with bipolar disorder themselves had the greatest understanding of the condition (mean rating = 8.1, sd = 1.9) followed by psychiatrists (mean rating = 7.6, sd = 2). Mental health professionals in general, (including community psychiatric nurses and clinical psychologists) were rated between 6.7 and 7 (sds = 2 – 2.3). GPs were rated to have the least understanding of bipolar disorder of all the professional groups listed (mean rating = 5.2, sd = 2.2). However, the general public were thought to have the poorest understanding of bipolar disorder overall, with a mean rating of 2.3 (sd = 1.4).

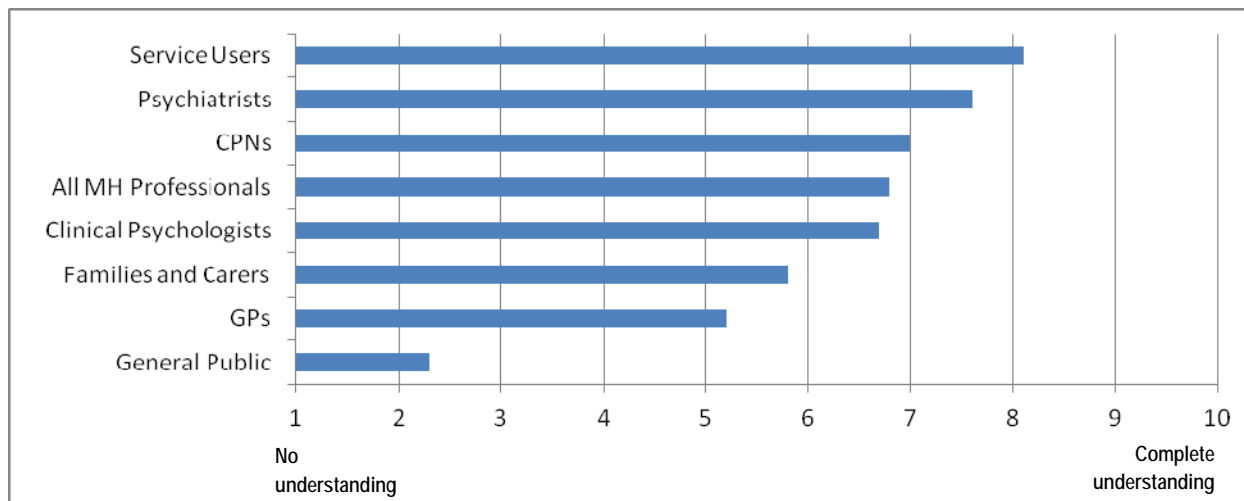


Figure 4.17 Participant ratings of bipolar disorder understanding within professional groups and the general public

NB: Respondents were also given the option to select 'don't know/no experience'. Thus means were calculated from only the people who provided a numerical rating. Less than 10% of people selected 'don't know/no experience' for all categories except CPNs, where 19.5% selected this, and clinical psychologists, where 30.5% selected this.

Carers, again, had very similar views to service users. They rated psychiatrists as understanding the most (Mean = 7.5, sd = 2.1), closely followed by service users themselves (Mean = 7.1, sd = 2.3) and clinical psychologists (Mean = 7.1, sd = 1.9). They rated family and friends' understanding at 6.6 (sd = 2.2). The professional group with the lowest rated understanding was GPs (Mean = 5.4, sd = 2.3) with the general public thought to have, by far, the lowest understanding overall with a mean rating of 2.4 (sd = 1.3).

4.5.2 Improving assessment and identification of bipolar disorder

Participants were asked about potential ways to improve the assessment and identification of bipolar disorder (Fig 4.18/Q17). They were asked to select any ideas which they thought would be helpful from a list which had been previously generated by the focus group. They were also able to add their own ideas in a free text response box when they selected the 'Other' option. The 262 participants selected a total of 1658 responses, identifying a mean of 6.3 possible ideas each for improving assessment and identification of bipolar disorder. The most frequently selected idea, with 200 people (76.3%) endorsing it, was that society should be more educated on mental health problems, as greater understanding would make it easier for people to seek and receive help. The second and third most frequently selected items were that GPs should have more training on bipolar disorder and that mental health trained professionals should carry

out assessments in primary care instead of GPs, chosen by 194 (74%) and 179 (68.3%) of people respectively. Only three people (1.1%) suggested that none of these ideas would be helpful, and one person (0.4%) thought that services did not need to be improved.

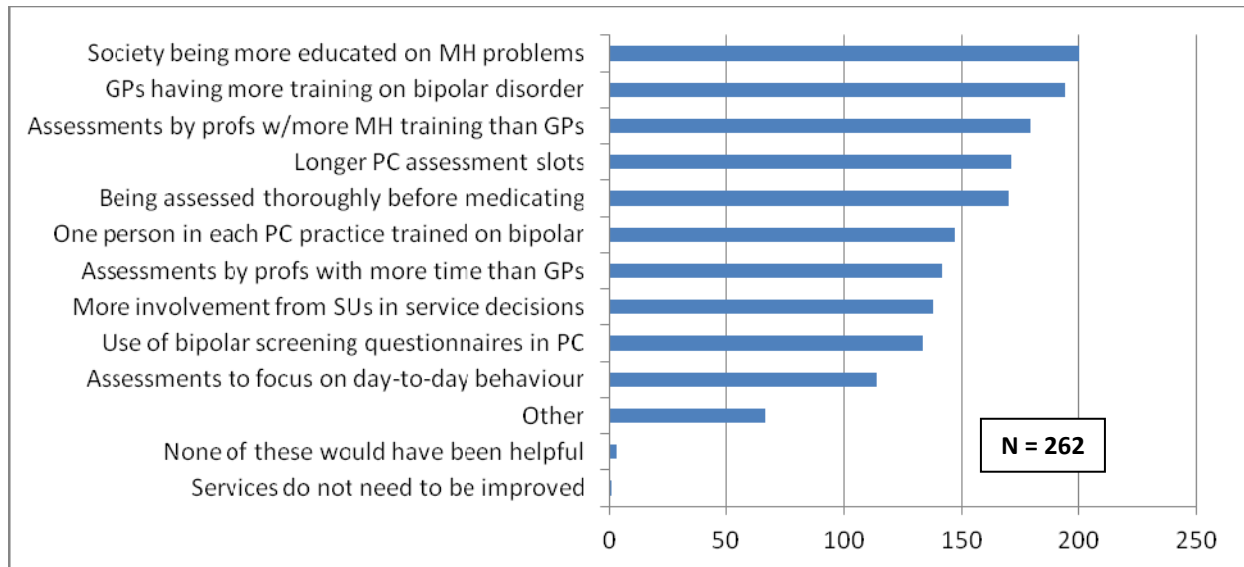


Figure 4.18 Number of respondents thinking each item would be helpful to improve assessment and identification of bipolar disorder

Of the 66 people (25.2%) who selected 'Other' and offered additional comments or ideas for improvements, there were a number of key themes, some of which were similar to those already listed, and some which offered new ideas. People thought that there should be the opportunity to talk through difficulties in more detail before being diagnosed and prescribed medication. People considered that medication, particularly antidepressants, should not be prescribed as casually as they often are, and that history taking and mood diaries should be a part of all mental health assessments. Consistency was considered to be an important factor, in terms of seeing the same professional repeatedly in order to build up a relationship. It was considered that diagnostic decisions should be discussed with a team, not just made by one individual. It was also generally felt that gatekeepers to mental health services should have better training on mental health and bipolar disorder in particular, and some thought that service users should be involved in carrying out this training, as 'experts by experience'.

Carers again had fairly similar ideas to service users about ways in which to improve the assessment and identification of bipolar disorder. 'Society being more educated on bipolar disorder' was the most frequently chosen answer, with 87.7% selecting this. 'Assessments by

those with more mental health training' was the second most frequently chosen, with GPs needing more training being third. Twenty carers (30.8%) included qualitative responses to this question. The stand out theme from these was an emphasis on the importance of consulting carers and involving them in the assessment process.

4.5.3 Helpful questions for GPs to ask

Four questions which had been suggested by members of the focus group as potentially helpful screening questions for bipolar disorder were included in the survey, and respondents were asked to consider whether they believed that these would be helpful questions for a GP to ask to identify whether a patient who presented with depression or other mental health problems might have bipolar disorder (Table 4.3/Q21).

Possible screening questions for GPs to ask	Number of participants agreeing question would be useful
a)'Have you noticed any changes in your mood recently, and has it affected your sleeping/eating/social relationships?' (e.g. a general exploration of how things are)	232 (88.5%)
b)'Have you ever experienced an unusually high mood?'	228 (87%)
c)'What did you do yesterday/this week? Then what? What time did you go to bed?' (e.g. just asking about daily activities to detect anything out of the ordinary)	201 (76.7%)
d)'When did you last feel happy? What were you doing?' (e.g. asking about periods of happiness to see if anything was more extreme than typical experiences of happiness)	192 (73.4%)

Table 4.3 Number of participants considering whether each of four questions would be helpful to screen for bipolar disorder

The majority of participants (over 70%) thought that all four questions would be useful, with only 19 people (7.3%) indicating that none were useful questions. Participants were also asked if they had ever been asked something like these by a GP. For question a) (Table 4.3) 86 people (32.8%) indicated that they had been asked something like this, but for the other three questions, less than 15% of people reported having been asked something similar by a GP. Over 70% of carers also thought that all four questions would be useful, but they rarely thought that the person they cared for was likely to have been asked questions like these.

4.5.3.1 Additional questions

Participants were also asked for their own ideas of any questions which would be useful for GPs to ask in order to identify whether someone might have bipolar disorder (Q22). This question was optional, and a response was provided by 120 people (45.8%). A number of question themes were identified from these responses.

Specific symptoms

Firstly, people thought that there were questions about specific symptoms that should be asked in a certain way. It was suggested that a detailed assessment of changes in sleeping and eating routines would be helpful. People also thought that it was important to ask about psychotic experiences, but that this should be done carefully, e.g. by instead asking about strange experiences or psychic powers, or simply about whether people think they know things that others do not. Productivity/creativity/ambitiousness should be asked about by enquiring about people's daily lives and achievements as well as their ideas and plans for the future. Risk taking and impulsivity should be enquired about, perhaps by asking people about 'out of character' behaviour, or things they have done which they regretted later. People indicated that it was important to ask about thoughts – in terms of racing thoughts 'running away with you' or any other changes, such as the way they may view other people, e.g. feeling superior or inferior compared to others. It was also thought that irritation, agitation and aggression were features of hypomania/mania which were often missed and should be asked about.

Other relevant factors

Service users identified that there were a number of other things that they thought should be enquired about. Importantly, people should be asked about their experience of mood cycles (preferably over a long period of time), especially how they may feel in-between periods of depression. Ideally, GPs should ask people to keep a mood diary over a few weeks and arrange a follow up appointment to review it. It was thought that people should not just be asked about 'high and low mood', but also about a range of different experiences. People also thought that it was important to ask about a family history of mental health problems, mood disorders and suicide attempts, as well as asking people about their own childhood experiences, and possibly asking them to complete a timeline of their own history. It was considered important to ask

people about major life events or stress and how these impacted on them. People also suggested that service users should be asked about concerns of family or friends, and if others had ever made comments about their behaviour. Ideally, patients would also be asked for permission to consult family or friends to additionally gather their observations.

General exploration and approach

Finally, people thought that questions should be more general and should be asked in certain ways. One suggestion was just to ask patients to 'tell me about yourself' (and use this strategy to pick up on things like speed of speech, grandiosity, ideas and achievements). Others thought that people should be asked directly 'do you feel like you might need some help dealing with strong emotional states?' or 'do you think there is anything wrong and what do you think it is?'

People also thought that similar questions should be asked on at least three separate occasions to detect changes in mood. The felt strongly that such assessments should take the form of individualised conversations, allowing for elaboration and exploration, rather than being a 'tick-box' exercise. It was considered that people could more easily 'fake' answers to 'tick-box' questions, but that a more general exploration would shed more light on how someone really was:

Mental health is not a fast quick-fix solution type of illness, or indeed a one-size-fits-all type of solution. It requires a great deal of time and patience. We all have different needs and we need to be treated with this taken into consideration and the usual tick-box type of help should be got rid of, or adapted and improved.

If you're in a high mood, answers to direct questions can be anything, so better to just have a general chat and also talk to family and friends network; high people can be very plausible (I know I was).

People also felt that the way in which questions were asked should be taken into consideration:

'The tone when asking the Q is v.important. I do not like feeling that I am being quizzed or put on the spot. For the GP to sound as if they are interested in what I am saying is useful.'

Carers' responses

Of the 65 carers, 35 (53.8%) provided a response to this question. Carers commented that questions should be asked tactfully, as service users may be sensitive to the way something is asked and may be less likely to be truthful if there is no rapport with the questioner. They again emphasised the importance of involving carers and asking them similar questions in order to gain a more objective understanding of the person's symptoms and behaviour. However, some carers commented that simply coming up with the right questions was not really the key issue:

These questions simply don't cut it nor would glibly adding a few more. GPs need training in mental health issues.

4.6 VALUE OF DIAGNOSIS

4.6.1 Accuracy of bipolar diagnosis

Participants were asked whether they thought that bipolar disorder was now the correct diagnosis for them (Fig 4.19/Q23). The vast majority (94.3%) indicated that they did think that they were now diagnosed with the correct illness.

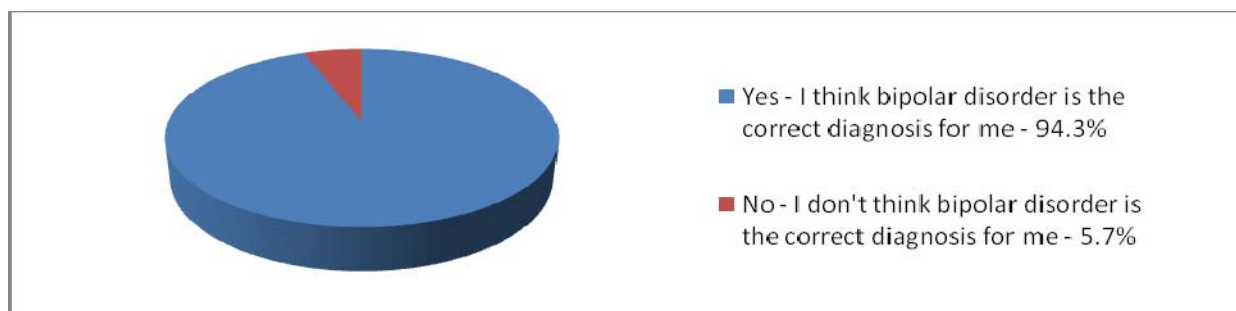


Figure 4.19 Percentage of respondents indicating whether they think bipolar disorder is the correct diagnosis

Similarly, 90.8% of carers indicated that they thought that bipolar disorder was the correct diagnosis for the person that they cared for.

4.6.2 Helpfulness of diagnosis

Participants were asked to consider how (if at all) having a diagnosis of bipolar disorder has been helpful to them (Fig 4.20/Q24a). People were asked to select each of the reasons why diagnosis may be helpful (these had been identified by the focus group) and were able to include their own comments by selecting 'Other'. The 262 respondents selected a total of 1504 answers, a mean of 5.7 answers each. Being able to make sense of their experiences and symptoms was the most commonly selected way in which having a diagnosis was thought to be helpful, with 231 people (88.2%) selecting this. The second most frequently chosen answer (217 people, 82.8%) was being enabled to gain more information about the condition. Similarly, over three quarters of respondents (201 people, 76.7%) indicated that a diagnosis had helped them to gain insight into the condition which had help them to then learn to manage it. Eight people (3.1%) indicated that having a diagnosis had not been helpful in any of the ways listed, and 49 people (18.7%) selected 'Other' (see Section 4.6.4).

In terms of carers, the most frequently chosen way in which a diagnosis was said to be helpful was also to help the individual make sense of their experiences, followed by 'gaining information' and 'access to medication' being the second and third most frequently chosen answers.

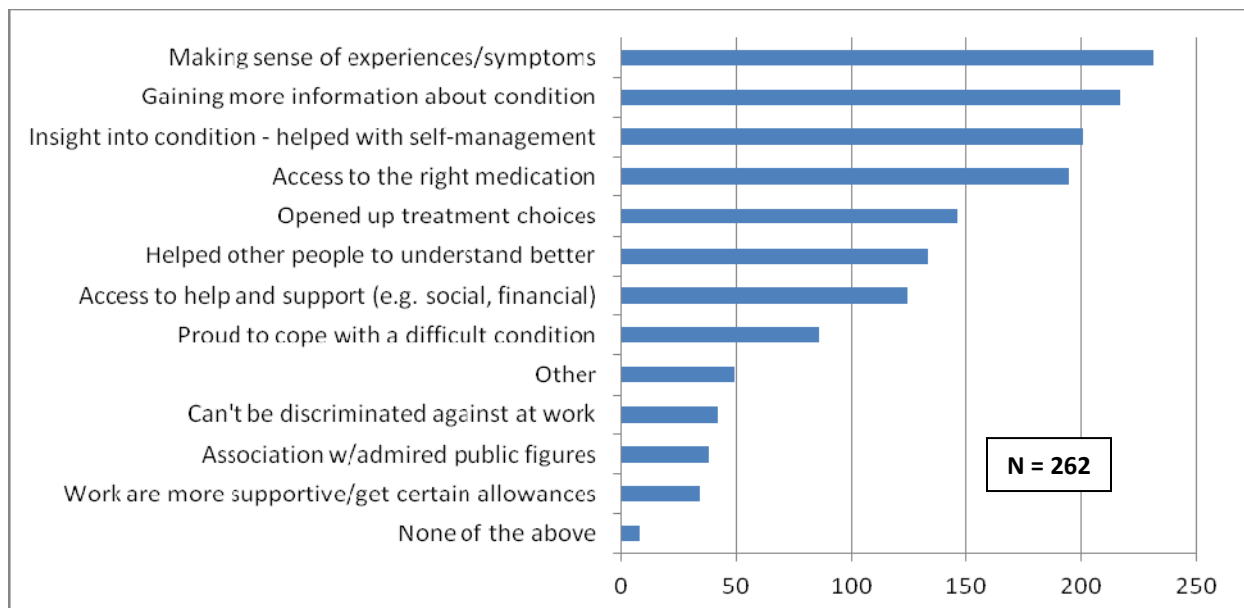


Figure 4.20 Number of participants considering each item to be a way in which a diagnosis is helpful

4.6.3 Unhelpfulness of diagnosis

Participants were then asked to identify how having a diagnosis of bipolar disorder was unhelpful to them (Fig 4.21/Q24b). They were asked to select all options that applied from a list generated by the focus group. Again, they were also able to select 'Other' in order to contribute their own ideas. The 262 participants chose a total of 1383 possible answers, an average of 5.3 answers each. Diagnosis was most frequently thought to be unhelpful due to having to deal with the social stigma associated with it (chosen by 173 people - 66%). People also found that being reliant on medication was a downside of having a diagnosis (151 people, 57.6%), and 148 people (56.5%) indicated that they worried about how others might react if they knew about the diagnosis. Ten people (3.8%) did not think that having a diagnosis was helpful in any of these ways, and 60 people (22.9%) selected 'Other' (see Section 4.6.4).

Carers most frequently reported the impact on self-esteem to be an unhelpful aspect of diagnosis, followed by reliance on medication and the reactions of others.

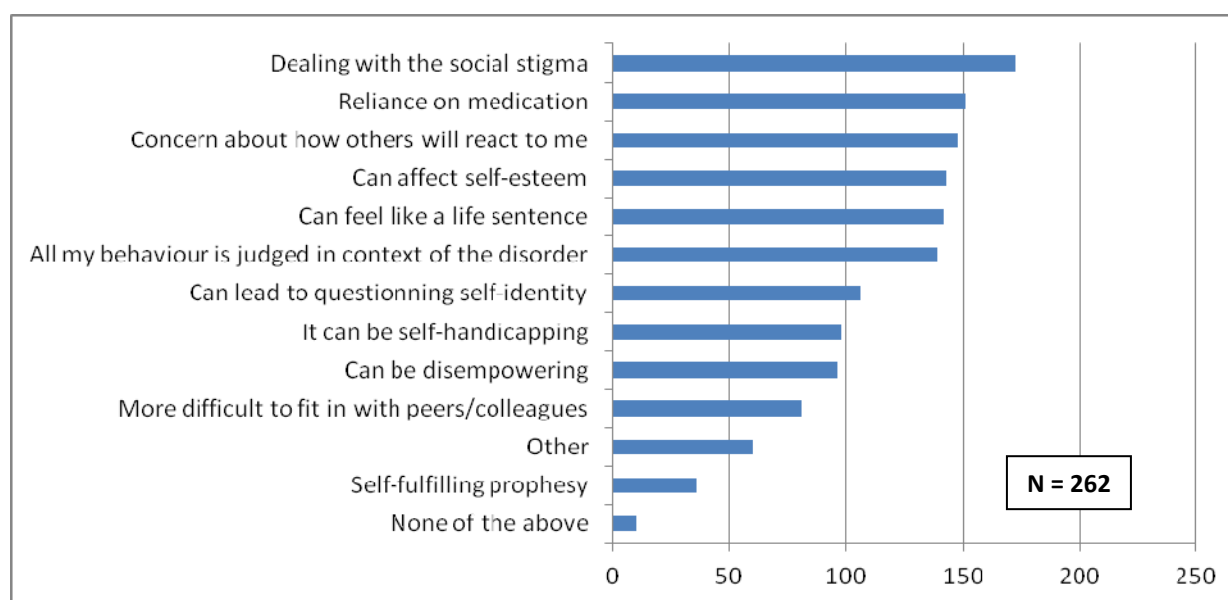


Figure 4.21 Number of participants considering each item to be a way in which a diagnosis is unhelpful

Notably, both service users and carers selected more reasons why a diagnosis was helpful than reasons why a diagnosis was unhelpful.

4.6.4 Views on diagnosis: qualitative responses

For service users who responded with additional 'other' answers to Q24a and b, there was considerable overlap between responses to the two questions, so these have been considered together. As a number of people offered different and detailed views on these topics, these identified themes are supported with additional quotes.

Support and understanding

People found that gaining support and understanding from other people who also have bipolar disorder, as well as being able to help and educate others, was a reason why having a diagnosis had value:

I have made new friends through the support group and various courses I have attended. It helps to be able to talk to people who also have the diagnosis.

For 3 years I was able to do 'Service User Involvement' work to help improve mental health services, which was very therapeutic.

It has allowed me to be more understanding and empathetic of others who are experiencing/have experienced mental health difficulties and I have supported their families.

Self-management

Respondents considered that a diagnosis helped them to understand their own risks and triggers, to manage them accordingly, and to protect themselves from the dangers of various high-risk scenarios:

I can now 'Google' for the right type of help. I was able to learn [that] half of the things I was doing in everyday life were making it worse. I changed my life to greatly improve my mental health.

It has helped me to give up drinking and smoking and to limit my caffeine intake, as I have realised that these activities can trigger my bipolar disorder.

It has kept me so far from following through with suicide.

Self-care

Respondents thought that having a diagnosis had helped them to be kinder towards themselves and less self-critical. It had also helped family members to avoid blaming themselves for the individual's experiences and behaviour:

I am a bit kinder to myself since I know I have lived with a serious disability for many years and still lived a good life.

It has helped my family understand that neither they nor me are to 'blame' for my behaviour at times.

The condition existing and having a name took away the feelings I had of being a freak because of what was going on in my head.

Relief

Many people expressed relief at finally having an explanation for their experiences.

Absolutely life-changing! Oh, how I wish I had been diagnosed when I was young!!!!

It has made me realize what has been the problem after all these years of being diagnosed with depression.

It was a relief to know what was wrong with me.

I can see ONLY positive aspects of receiving a diagnosis.

Personality versus illness

There were differing views of the way in which bipolar disorder was conceptualised. Some people found the diagnosis helpful when the disorder was viewed as a biological condition or illness, which was out of their control, whereas others preferred to think of bipolar as not so much as an illness, but a personality trait that they identified with:

Receiving the diagnosis wasn't useful until I learned it was biological - not a character defect. Once I knew it was biological, I knew I had to keep trying drugs, that drugs were absolutely necessary.

I do not think any label of this kind is helpful. I am just me, I am unique and my "illness" is not an illness at all, in my view, but just part of my personality.

Self-doubt

Some people felt that a negative aspect of having a diagnosis was that it had led them to question themselves and to feel like other people might question their judgement and abilities as a consequence of the diagnosis:

Makes me feel lonely, depressed with no confidence.

It has made me not trust my own judgement.

I have lost credibility with many people, and my ideas have been discounted even when well founded.

My family and friends (those that remain, a 'diagnosis' certainly sorts them out) do not treat me the same way anymore. I have lost my independence and my confidence and have to try hard to find purpose in life.

Influence of the media

Many people had views on how bipolar disorder is portrayed in the media and it was felt that this was both helpful and unhelpful for people with the diagnosis.

Even close friends don't understand, really. I don't spend time trying to explain because the media can put negative images of mental health - people as being violent nutters.

I also don't like some of the publicity surrounding it and I have been told I have a glamorous illness which is quite insulting really as there was nothing glamorous about my journey. I think the publicity and stars have helped in some ways but in other ways it has been damaging.

Bipolar in TV 'Soaps' has been a good idea and is quite educational for the general public.

I get annoyed by suggestions in the media that bipolar disorder is somehow glamorous and celebrities publicising the fact they have bipolar disorder as if it's almost something fashionable. This sort of slant gives no indication of how disruptive the condition can be.

Discrimination

Many people disagreed with the idea in Q24a that a having a diagnosis had been helpful for gaining support in the workplace. Many felt that they were still discriminated against in this setting as well as by other agencies:

I was discriminated against when starting a nursing course at university and when applying for jobs as a nurse. We are told that employers are not allowed to discriminate against people with bipolar disorder - but they can get away with it as long as they are subtle about it!

Problems getting work when declared, problems with travel insurance, discrimination from DVLA.

Receiving a diagnosis of bipolar disorder and seeking accommodations at work for it caused me to lose my job and needing such accommodations has prevented me from finding a more suitable job.

We were discriminated against when applying for adoption assessment on grounds of my diagnosis despite my consultant's support.

Stigma and lack of understanding

People were of the view that stigma in society is still very much a problem for people with bipolar disorder, and that it is often easier to tell no one than to expect others to understand:

The diagnosis is helpful to me and immediate family and my GP and other Health people. It is totally unwise for anyone else to know because they do not understand and treat you with wariness. I do not tell anyone even family outside of immediate family. I keep it to myself so I am treated normally without gossip and comments being made. It does not help other people to understand me better.

I don't tell anyone. People will never understand ... even when you speak to some mental health people they don't really understand so it will be impossible to expect the general public to understand.

A lot of rubbish is talked about being accepted in society with bipolar; that is absolute 'bull' of course you are discriminated against. I haven't told a soul.

Carers' perspective

There were 23 qualitative responses provided by carers to questions 24a and b. Themes relating to the helpfulness of diagnosis included the idea that acceptance of diagnosis could facilitate better management of the condition and improve confidence and quality of life for individuals. It could also facilitate repairing any difficulties occurring during an episode, especially when other people were involved.

Other carers were of the view that the diagnosis itself could make depressed episodes worse, due to an increased sense of hopelessness experienced by the service user. Carers also commented that the diagnosis could provide 'an excuse to misbehave', leading to more extreme addiction-related behaviour and less remorse over consequences.

4.6.5 Preference of diagnosis

Bearing in mind the advantages and disadvantages of having a diagnosis of bipolar disorder that respondents had considered in the previous two questions, they were then asked whether they would rather have the diagnosis to explain the things that they were experiencing, or no diagnosis at all (Fig 4.22/Q24c). The majority of people (86.2%) indicated that they would rather have the diagnosis, leaving 8% undecided and 5.7% suggesting that they would rather not be diagnosed with bipolar disorder.

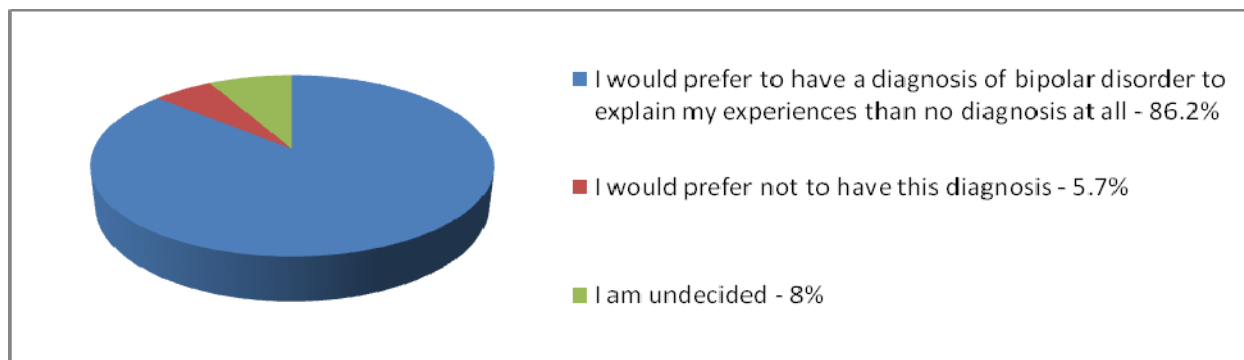


Figure 4.22 Percentage of respondents indicating whether they would prefer to have a diagnosis of bipolar or no diagnosis

The majority of carers (92.3%) agreed that they would rather the person they cared for had a diagnosis, with the remainder (7.7%) being undecided.

4.7 ADDITIONAL COMMENTS

The final question of the survey (Q25) asked respondents whether they had any further questions, comments or thoughts about any of the issues raised during the survey. This question was optional, and 102 service users (38.9%) and 38 carers (58.5%) provided answers on a variety of topics. Some people shared positive and negative stories of how they or the person they knew had managed the condition since diagnosis, as well as more general topics related to bipolar disorder and feedback on the survey itself. Bearing in mind the original aims of the survey, six key areas were identified. Quotes below were given by service users unless preceded by an asterisk (*) indicating that these responses were from carers.

4.7.1 Views on professionals

Respondents generally thought that GPs and healthcare professionals needed better training on bipolar disorder and should understand the condition better:

I think one big problem is that a lot of healthcare professionals seem to have a very 'black and white' view of bipolar disorder and fail to recognise the more subtle symptoms. Unless someone spells it out to them or is having the very typical/obvious euphoric manic symptoms - they just don't get it!

I trained as a psych nurse myself and we had only one lecture on bipolar disorder - and it focused on the very basic. No wonder the diagnosis gets missed.

I have good friends who have gone out of their way to read about and understand my illness. So why is it so hard for health professionals to understand, and learn how to deal with it properly?

I think that GPs should have much more knowledge about mental issues.

I really wish GPs were better trained to diagnose bipolar disorder. It was only when I went to my GP with a diagnosis from a rather crude online test, that he sat up. Professionals need to spot crises. I failed a suicide attempt - no one saw it coming.

The two biggest hurdles after things became acute were the lack of awareness of GPs and the lack of time on a GP visit to work towards a diagnosis.

The medics just don't accept they make mistakes- in this case nearly my marriage and reputation.

**I think GPs do not consider bipolar at all unless pointed out by patients or their family.*

4.7.2 Views on medication

Participants who discussed medication generally had negative views of the effects of antidepressants. People also expressed frustration at having had to try various combinations of medication, many of which were unhelpful and carried unpleasant side-effects, as well as the overreliance on medication to treat bipolar disorder:

Before and after my diagnosis in 1998, I had to go through many costly NHS bureaucratic processes and assessments that resulted in little help and in being put on a combination of over 22 different drugs over the years that didn't work and often made me worse or suicidal. I was put on several SSRI/SNRI drugs after my diagnosis as well, which were dangerously ineffective.

I seriously believe antidepressants caused me to be bipolar.

Don't give antidepressants to people whose mother and sister have/had bipolar!!

I'm quite certain this destabilization is from the antidepressant, and the moral is that GPs and mental health professionals would benefit from knowing more about atypical presentations of bipolar (rapid-cycling, mixed states etc) and the destabilizing potential antidepressants can have over time.

I would have liked more information from GP and MH teams to focus on ways of improving my own condition based on lifestyle and food intake rather than just feeling that medication was the only answer.

**I believe that the reason my wife experienced psychotic episodes in 2003/2004 was that she was on a high dose of Venlafaxine treating her depression and this wasn't stopped when she first displayed hypomanic behaviour. NICE guidelines now advise that antidepressants should be stopped immediately and my wife's current psychiatrist is well aware of this. I wonder how many medical professionals are familiar with the NICE guidelines for treating bipolar.*

**In our particular case, being that our son is so young, he didn't experience the bipolar hypomania until the antidepressants were given.*

4.7.3 Views on early diagnosis

People generally commented that they would have preferred to be diagnosed earlier, although a few respondents indicated that they did not think that they should have been diagnosed sooner, especially if they had functioned well previously:

So I was pleased to be diagnosed but regretted that an earlier diagnosis might have allowed me to lead a more productive life. I think early diagnosis is really important - as long as it's right!

Having the depression diagnosis no-one ever really listened to how I felt or paid any attention to my moods or feelings. Eventually I managed to speak to my psychiatrist about my extreme mood swings and the fact I was up all night doing housework etc. As a result she changed my diagnosis to bipolar, which should have happened much sooner.

I presented with depression a number of times, it passed on its own or with short term treatment. Everyday mood was good, sometimes exuberant, but never got me into trouble. In July 1998 I went hypomanic. Then sectioned and diagnosed. Coped with this at 39, would not have liked a diagnosis sooner. But then, prior to this I had done well at work and was enjoying being a Mum.

4.7.4 Views on care after diagnosis

People were of the view that early recognition and diagnosis served a purpose as long as appropriate care was available afterwards. However, they indicated that such care was often inadequate:

After diagnosis, what support does anyone actually receive, especially in view of budget cuts?

**An issue is how to continue to find consistent support once they have the diagnosis, and how to get better treatments.*

**I wish I could help more with getting his life back on track. The follow-up care is basic.*

4.7.5 Importance of including carers

Some service users, and in particular carers, expressed strong views on the importance of including carers in both the assessment and management of bipolar disorder:

**I would just stress the importance of involving the carer in the treatment of the person. When he was first diagnosed, I felt excluded from the whole process even though it affected me. In more recent years, things have improved and I have felt more included in the treatment which is better for him and for me.*

**Carers or partners should be considered as part of the mental health team, if they wish, and involved in the ongoing treatment and stabilisation of the person cared for.*

**I think mental health professionals should spend more time explaining to family and carers about the condition. Also no health professional asked US how he behaved. If they had signposted some of the symptoms of bipolar we might have had an earlier diagnosis.*

4.7.6 General survey feedback

As an aim of this research project has been to consider service user and carer opinion on the relevance of the topic area itself, this section has been included to summarise respondent feedback. The majority of comments (included in responses to Q25) about the content and aims of the survey were very positive and indicated that the research was relevant and valued from a service user and carer perspective, and that they appreciated the opportunity to be able to contribute their opinions. The few negative comments (See Appendix L for all comments) were related to the usability of the survey rather than the nature of the research itself, such as the wording of the questions and the fact that not every question applied to everyone.

Thanks for your research. I hope it helps people with bipolar receive treatment earlier in their lives!!!!

I think this is an excellent survey, the questions are really good and its one of the best surveys I have ever done. I hope it helps in some way and I wish I could tell you more. It would be great if there were more opportunities like this and even more interviews face-to-face to get as much information from people and therefore gain a greater understanding of mental health problems.

The questions in this survey were really well put together, made me think a lot about my experiences of having bipolar and made me realize that a lot of my most difficult experiences in life before diagnosis could have been avoided/managed better if I had had the right diagnosis, treatment and support.

This is an excellent direction to be going in and should prove extremely helpful if it results in wider education about bipolar to GPs and other professionals, not to mention family and the public.

Very well thought out questions that I believe, if taken up, will stop people having a miserable 16 years of not knowing what was wrong, like myself. Well done!

**I am pleased to be able to help with this survey, I don't think the carer's voice is heard enough. They can provide so much valuable information but are more often than not ignored.*

4.8 ADDITIONAL ANALYSES

4.8.1 Gender differences

Responses for males and females were compared and fairly similar patterns were evident, with a few notable differences which will now be described. For men, first signs of bipolar disorder were most likely to be similar to mixed moods (42.4% of males), whereas for females, they were most like depression (43.5% of females). Whilst both genders were most likely to seek help for depression, at the time of diagnosis, men were most likely to be experiencing mania (31.8%) and females were most likely to be experiencing mixed moods (32.2%).

Females were more likely to think that they had been previously misdiagnosed than men (77.8% thought this as opposed to 70.6%), and also more likely to think that they should have been diagnosed sooner (82.4% versus 75.3%).

Females were likely to experience onset of affective symptoms at a younger age than males, with first depression occurring at a mean of 16.3 years and first signs of bipolar disorder occurring at a mean age of 17.5 years. Men were likely to be over 20 years old when they first experienced depression or signs of bipolar. This gender effect was significant for both first depression ($t(254) = 3.71, p < .001$) and first signs of bipolar disorder ($t(260) = 2.26, p < .05$). Although this also led to a longer delay between first signs of bipolar and diagnosis (a mean of 15.5 years for men and 16.7 years for women), as well as first help-seeking and diagnosis (11.9 years for females and 9.8 years for males) this difference in the delay itself was not statistically significant.

4.8.2 Experience when sought help and length of diagnostic delay

The mean length of time people waited between seeking help for bipolar symptoms and receiving a diagnosis was compared depending on the type of symptoms they were experiencing at time of help-seeking. Those who were experiencing depression when they first sought help experienced the longest delay of 12.9 years before they were eventually diagnosed. Those experiencing mixed moods or a range of other symptoms waited approximately 10 years. Those who sought help when experiencing mania or hypomania waited much less time - just over four years (Fig 4.23).

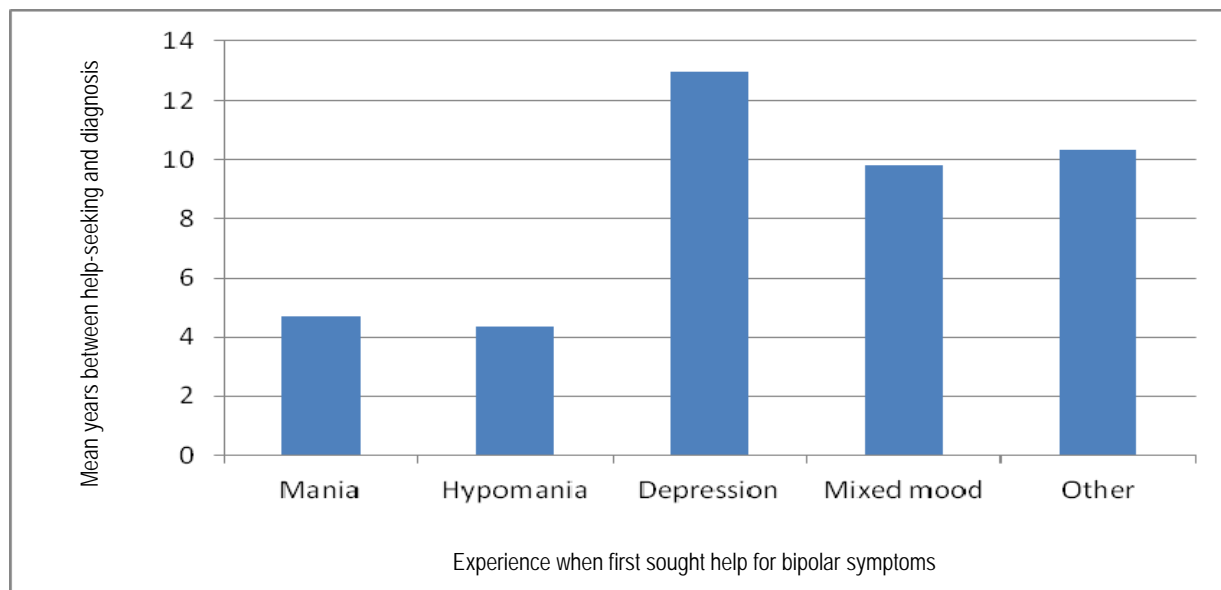


Figure 4.23 Mean diagnostic delay (in years) depending on symptoms when first sought help

4.8.3 Onset of illness and delay in diagnosis

Age of self-reported first signs of bipolar disorder was compared with length of diagnostic delay (the time between first help-seeking for bipolar symptoms and being diagnosed with bipolar disorder) in order find out if those who experienced a younger age of onset would also experience longer delays. A significant negative correlation was found ($r = -.33$, $p < .001$) indicating that as people get older the delay in diagnosis gets shorter supporting previous findings to this effect.

4.8.4 Time since diagnosis of bipolar disorder and length of diagnostic delay

Some qualitative comments referred to the idea that people had had bad experiences themselves but hoped that the situation was now improving. However other results suggest that people are experiencing even longer delays in diagnosis and are more frequently misdiagnosed than reported in studies carried out almost a decade ago (e.g. Hirschfeld *et al.*, 2003). Accordingly, whether any improvements had occurred within the current sample was investigated, by comparing the length of time since people were diagnosed, and the length of diagnostic delay they had experienced. This comparison yielded a significant negative correlation ($r = -.31$, $p < .001$) indicating that diagnostic delay had in fact increased the more

recently respondents were diagnosed, which suggests that the situation is not improving and may actually be getting worse.

4.8 SUMMARY

The results of this survey indicate that a number of difficulties exist in the process of being diagnosed with bipolar disorder from a service user and carer perspective. The majority of respondents believed that they should have been diagnosed with bipolar disorder sooner and experienced delays of over eleven years between attempting to seek help for bipolar symptoms and being diagnosed with the condition. Almost a third of participants had attempted to seek help from a doctor over 20 times before being diagnosed with bipolar disorder, and over three-quarters considered that they had first been misdiagnosed with other conditions, which might have contributed to a delay in receiving the right help. Respondents considered that many issues with the timely identification of bipolar disorder lie with GPs, and that knowledge, understanding and assessment of mental health is poor in primary care. However, participants contributed a number of ideas and potential strategies for improving the assessment and recognition of bipolar disorder, especially regarding the questions asked to service users. Respondents also reported a number of ways in which their diagnosis of bipolar disorder had been helpful to them as well as ways in which it had been unhelpful. Related to this, they also felt that the general public and society as a whole has a poor understanding of bipolar disorder (despite recent attention in the media) and that those affected by it still face considerable stigma and discrimination.

CHAPTER 5 – DISCUSSION

5.0 OVERVIEW

The following chapter will discuss the overall study outcomes compared to the initial aims and how the focus group results contributed to the survey development, followed by a more in-depth discussion of the survey results. These will be considered in relation to the existing research literature, and key implications and the clinical relevance of the results will be discussed. Strengths, methodological considerations and limitations will then be covered, with a view to suggesting possible future research directions.

5.0.1 Summary of study aims and outcomes

The principle aims of this study were to explore the process and meaning of being diagnosed with bipolar disorder from a service user perspective. This was done by first convening a service user focus group to explore issues relating to a bipolar diagnosis thus informing the development of an online survey on this topic. The survey then aimed to gather information on experiences and opinions about the process of diagnosis from service user and carer members of the charity Bipolar UK.

Four service users took part in a two hour focus group discussion. The transcript from this was then analysed thematically, and seven themes and a number of sub-themes were identified which were then used to inform the development of the online survey (See Table 3.1). The survey was then launched online and was made available to be completed over a two month period. A total of 327 people (262 service users and 65 carers) completed the survey and contributed their views on the process of being diagnosed with bipolar disorder. Survey results indicated that people faced considerable problems in relation to their diagnosis of bipolar disorder, including average delays of over eleven years, being misdiagnosed with other disorders (notably depression), difficulties with medication and issues with professionals. Respondents also offered views on how services could be improved as well as describing the impact that the diagnosis had had on them. See Section 5.2 for a detailed discussion of survey aims, results and how these relate to the existing literature.

5.1 FOCUS GROUP AND SURVEY DEVELOPMENT

This section will consider how the seven themes identified from the focus group transcript relate to the content of the survey. Overall, focus group members considered the topic area to be an important one and felt that research into it would be worthwhile. The seven themes identified in the focus group transcript were:

- 1) Meaning and implications of a bipolar diagnosis
- 2) Awareness, knowledge and understanding of bipolar disorder
- 3) Issues with the process of assessment and diagnosis
- 4) The impact of bipolar symptoms on seeking and receiving help
- 5) Unmet service needs regarding assessment and diagnosis
- 6) Professionals differ on their approach to mental health
- 7) Improving assessment and diagnosis

5.1.1 Meaning and implications of a bipolar diagnosis

Theme 1 captured the ambivalence experienced by people with bipolar disorder towards their diagnosis. Participants identified a number of ways in which their diagnosis was helpful as well as unhelpful to them. They also identified with the diagnosis in different ways; it could be viewed as something which increased their self-confidence, or in other situations it could be self-limiting. Overall, focus group members seemed to accept and in most cases to be relieved to have their diagnosis of bipolar disorder to explain their experiences. This theme informed survey questions 23 and 24, asking about the accuracy, helpfulness and unhelpfulness of diagnosis, and whether respondents would prefer an alternative explanation. The focus group ideas formed the list of possible response options in Q24a and Q24b.

5.1.2 Awareness, knowledge and understanding of bipolar disorder

Theme 2 referred to service user views that different professional groups and parts of society had differing levels of knowledge and understanding of bipolar disorder. They also thought that, at times, professionals who might have been expected to know about the condition didn't understand it as well as service users themselves did. They also expressed a view that due to increased media attention, the general public may assume that they understand about bipolar,

but that the reality experienced by service users was very different from the recent ‘celebrity endorsed’ picture. This theme informed Q16 (understanding of bipolar disorder in different groups), Q14 (barriers to getting help) and Q17 (overcoming barriers).

5.1.3 Issues with the process of assessment and diagnosis

Theme 3 related to participant views on and personal experience of the issues with diagnosis reported in the research literature. Delay between symptom onset and appropriate diagnosis was considered to be a problem for many, as well as difficulties associated with being misdiagnosed with other conditions, notably depression. Two participants had experienced undesirable effects following antidepressant use. Bearing these perspectives in mind, the survey set out to ask about people’s pre-diagnosis experiences of symptoms, help-seeking, previous diagnoses, antidepressant use and eventual diagnosis with bipolar disorder. See Q9 to Q15.

5.1.4 The impact of bipolar symptoms on seeking and receiving help

Theme 4 captured the participants’ acknowledgement that there are many features of bipolar disorder which may affect people’s styles of help-seeking. Participants thought that people were most likely to seek help for depression. They thought that people were likely to lack insight when experiencing mania or hypomania and that, after the event, they may not recognise such symptoms as relevant. However, participants did think that people would sometimes recognise that aspects of their manic/hypomanic symptoms were becoming unmanageable, and try to seek help in these instances. This theme informed Q12, regarding whom help was sought from, symptoms at the time of help-seeking, and factors influencing receipt of help.

5.1.5 Unmet service needs regarding assessment and diagnosis

Theme 5 considered the idea that there are shortfalls in care for people with bipolar disorder, particularly when it comes to primary care practice. Participants expressed views that mental health was not taken seriously enough, that staff were inadequately trained and that not enough time was allocated to mental health assessments. This theme also contributed to Q14 and Q17 (barriers to help and overcoming barriers).

5.1.6 Professionals differ on their approach to mental health

Theme 6 related to participants' views that some professionals were very competent, whereas others showed a significant lack of understanding with regards to mental health and bipolar disorder. Participants considered that this knowledge could differ within and between professionals. GPs were the topic of many conversations, and were discussed in both a positive and negative light, although the general view was that they, as a profession, should be more informed on mental health issues. Participants also suggested that they appreciated the understanding approach taken by non-medically trained professionals. This theme informed Q16 of the survey, which asked about different professionals' understanding of bipolar disorder in order to gauge an overall perspective of how service users rate different professional groups.

5.1.7 Improving assessment and diagnosis

Theme 7 captured participants' ideas for improving the assessment and diagnosis of bipolar disorder. They came up with a number of possibilities, including increased mental health training or improved access to those with this training, more detailed assessment methods (some of which might involve other family members) and the use of screening questionnaires. These ideas informed response options for Q17 (improving the recognition of bipolar disorder). Participants also suggested a number of risk factors or early identifiers which professionals could be alert to, which informed Q18 to Q20. In addition, the group came up with a number of specific questions which they suggested might be helpful for GPs or other professionals to ask, which were included as part of Q21.

5.2 INTERPRETATION OF SURVEY RESULTS AND LINKS TO EXISTING LITERATURE

5.2.1 Demographic characteristics

Of the 262 service user respondents, 68% were female. Whilst most epidemiological studies indicate that similar numbers of males and females experience bipolar disorder (Kawa *et al.*, 2005), previous survey studies (Hirschfeld *et al.*, 2003; Morselli & Elgie, 2003) report a similar ratio of female to male respondents to the current study. Participant mean age of 47 years was also similar to these studies. Fewer participants reported that they were unemployed (16%) than the 37% found by Hirschfeld *et al.* (2003); however, this could have been partially due to

different available response options in the current study (e.g. voluntary work). However, the low unemployment rate suggests that respondents in the current study are reasonably high functioning. The majority of participants (88%) accessed healthcare in the UK, indicating that survey results can broadly be generalised to UK based services. In terms of the type of diagnosis, most people (81%) indicated that they had had experiences consistent with a diagnosis of bipolar I. This is surprising considering that bipolar II is thought to occur more frequently, and the problems related to delayed and misdiagnosis are also thought to be more likely for people with bipolar II. However, it is possible that these questions were misinterpreted as they did not ask directly about type of diagnosis (a decision made following focus group feedback), so numbers regarding type of bipolar diagnosis based on responses to these questions may not be reliable. Notably though, when asked about symptoms of bipolar disorder prior to and at the time of diagnosis (Section 4.2.2) respondents were more likely to report the experience of mania and rarely reported hypomania, suggesting that more respondents may have had a presentation consistent with a bipolar I diagnosis.

Notable differences in carer demographics were that they were on average over ten years older than service users (age 58 years) and, accordingly, a high percentage were retired (46%). A large proportion were also married (72%). The percentage who were female was also lower (59%) than for service users, although male respondents were still a minority.

5.2.2 Aim a) Service user experiences of the diagnostic process

As outlined in Figure 4.3, participants had experiences of significant mood disturbance long before they were diagnosed with bipolar disorder. Depression tended to be experienced earliest, at age 17.7 years, with what were considered to be the first signs of bipolar around six months later, at age 18.4 years. Symptoms of mania/hypomania first occurred in the early twenties (22.3 years) and people first tried to seek help for bipolar symptoms one year later at 23.3 years. According to survey respondents, an average of well over a decade then passed before they were diagnosed with bipolar disorder at the age of 34.7 years, which was also over 15 years since people first reported experiencing signs of bipolar disorder. This time between first symptoms, first help-seeking and eventual bipolar diagnosis suggests a significant delay from the point of view of service users. This study focussed on the delay between first help-seeking and diagnosis, as this seemed to most appropriately represent delay from a service user

perspective (e.g. they may have experienced symptoms before this, but not wanted or needed help for them, so the delay from their perspective begins at the time of wanting help).

Berk and colleagues (2007) found that participants reported a similar age for first depressed symptoms, first manic symptoms and first help-seeking to respondents in the current study. However, in this study the first diagnosis of bipolar disorder was received at an average age 30, suggesting a delay between help-seeking and diagnosis of about six years. Other studies reported a similar delay (Morselli & Elgie, 2003) although the DBSA survey studies (Hirschfeld *et al.*, 2003; Lish *et al.*, 1994) found that over a third of respondents experienced a delay of over 10 years. However, participants in the current study indicated that they experienced *an average* of over eleven years delay between help-seeking and diagnosis. This even longer delay could represent the differences in services in the UK (other studies were carried out in Australia, Europe and the USA) as it seems that symptoms themselves were not experienced any earlier, but that the diagnosis occurred almost five years later.

People's first experiences of mood symptoms were most likely to be depression or mixed moods (78%) with a minority first experiencing mania/hypomania. Respondents were by far most likely to be experiencing depression when they sought help (60%). However, when actually diagnosed with bipolar disorder they were most likely to be experiencing mixed moods (33%) or mania (27%). This suggests that people who develop bipolar disorder are likely to experience depression or mixed moods first, rather than the mania which is more typically associated with the condition. In particular, the frequent occurrence of mixed moods/mood swings as a first sign warrants attention, and could be a key area to consider when screening for bipolar disorder. People are most likely to seek help themselves for the experience of depression, yet for bipolar to be identified they are more likely to be in a manic or mixed phase. This indicates that bipolar is only detected when symptoms are obvious, and when people present with depression other previous mood states are not enquired about by professionals or not reported by service users. This is emphasised in Figure 4.23, which shows that those who first seek help for depression wait almost 13 years before being diagnosed with bipolar disorder, and those who seek help for mixed moods wait almost 10 years. However, those who seek help for mania or hypomania wait much less time: just over four years. Previous research also highlights the fact that service users are most likely to experience depression first and to seek help for depressed symptoms (Ghaemi *et al.*, 2002; Judd *et al.*, 2002) and under-report manic symptoms (Lewis, 2004). However, the importance of mixed states in the early stages of bipolar disorder has not previously been a research focus.

For men in particular, first signs of bipolar disorder were most likely to be similar to mixed moods, whereas for females, first signs were most likely to be depression. Females were likely to experience these early signs at a younger age than males, and may face a longer delay before being diagnosed. It is possible that the course of bipolar disorder for women may be slightly less 'typical' and more dominated by depression than for males, which may make it even more difficult to identify bipolar disorder early in this group. A larger percentage of females than males also thought that they should have been diagnosed sooner. If issues with diagnosis are even more relevant to females, this could be one explanation for the uneven gender split of survey respondents.

Unmanageable symptoms were considered by the highest number of people (58%) to be a reason for first help-seeking. This reason could include a number of other options relating to specific symptoms. However, sleep disturbance specifically was the second highest rated factor (42%). The suggestion by family and friends to seek help was the third highest rated factor (39%), indicating that the influence of support networks could encourage earlier help-seeking, especially if someone does not have insight into the dangers of their own high moods. Worryingly, 18% people first sought or received help following a suicide attempt. This highlights the potential risks of unrecognised bipolar disorder, as earlier access to help might contribute to such severe consequences being avoided.

The majority of people first sought help for their bipolar symptoms from their GP (60%), yet almost a third of participants (29%) indicated that they had consulted a medical professional over 20 times with bipolar symptoms before receiving a diagnosis of bipolar disorder. A conservative estimate of mean number of consultations across the sample was over 10. This question was also asked in the USA-based DBSA survey (Hirschfeld *et al.*, 2003), where respondents reported a mean of four consultations before diagnosis. Results from the current study suggest that the situation may be worse in the UK, or that GPs' ability to recognise bipolar has deteriorated in the last decade. It seems that people are going to their GP first for help, but possible bipolar disorder is repeatedly not being identified. Eventual diagnosis was most frequently (in 86% of cases) carried out by a psychiatrist, and only 11% of people were diagnosed by their GP. It may be that GPs generally do not feel it is appropriate to diagnose an enduring mental health condition such as bipolar disorder in primary care practice. However, the number of consultations indicates that people may not be being referred on to specialist services within an appropriate timescale for a more detailed assessment to take place.

5.2.3 Aim b) Service user reports and previous research

The results described above suggest that service users experience considerable diagnostic delay, as previously suggested in the research literature, but it is possible that they may not have viewed this as a problem themselves. However, the vast majority (over 80%) indicated that they thought that they should have been diagnosed with bipolar disorder sooner, implying that this is a real issue from a service user perspective.

Berk and colleagues (2007) reported that those with a younger age of onset of affective symptoms experienced greater delays before being diagnosed. In the current study this was investigated by comparing age of first signs of bipolar disorder with length of diagnostic delay. A significant negative correlation was found, supporting these previous findings. This presents a concern for young people with emerging bipolar disorder, especially as the teenage years are often characterised by volatile moods for many who may not go on to develop mental health problems. This means that differentiating between which experiences are problematic and which are not may not be straightforward. Focus group participants also thought it inappropriate to diagnosed someone under the age of 20 with bipolar disorder. However, the issue is not that diagnosis is being delayed a couple of years until people are no longer teenagers; it is that people experience delays of over a decade. As those who experience the longest delays can face the most unfavourable outcomes (Gazelle *et al.*, 2005) this could be an issue for young people with possible bipolar disorder.

Over three-quarters of participants also thought that they had been misdiagnosed with another disorder prior to being diagnosed with bipolar disorder. Of those who thought that they had been misdiagnosed, 14% reported that it had happened over ten times, with a mean of at least two different misdiagnoses. By far the most likely misdiagnosis was depression, affecting 92% of those misdiagnosed (69% of the whole sample), although anxiety disorders were the second most likely misdiagnosis, affecting 33%. In previous studies approximately 55% to 70% of participants were misdiagnosed (e.g. Berk *et al.*, 2007; Hirschfeld *et al.*, 2003) with the most frequent misdiagnosis being depression. Primary care studies assessing patients diagnosed with depression for potential bipolar disorder have also found that over 20% are likely to have bipolar disorder (Hirschfeld *et al.*, 2005; Smith *et al.*, 2011). In terms of anxiety disorders, a high comorbidity with bipolar disorder is often reported (e.g. Merikangas *et al.*, 2007) but, as this study indicates, it may serve to mask underlying bipolar disorder. The results of the current study add to this evidence that a large number of people with bipolar disorder are misdiagnosed

with depression or another disorder, and that, importantly, service users consider themselves to have been previously misdiagnosed.

A major concern about the misdiagnosis of bipolar disorder as depression (and, to an extent, anxiety) is the use of antidepressants. Of participants who reported being misdiagnosed, 96% indicated that they had been prescribed antidepressants prior to bipolar diagnosis, and 74% of those reported that they had experienced mania/hypomania whilst taking them; for 31% this was their first episode of high mood. Taken as a whole, over half the sample had experienced mania/hypomania whilst taking antidepressants. This evidence adds weight to concern about the unhelpfulness of antidepressant monotherapy for people with potential bipolar disorder (Rybakowski, 2011) as well as risks of this form of medication inducing mood switches in some people. Yet it is apparent that antidepressants are frequently prescribed for what is thought to be depression without such a prescription being preceded by a thorough assessment.

5.2.4 Aim c) Service user explanations of issues

Participants most frequently attributed their own lack of insight into their symptoms when experiencing mania/hypomania as a barrier to bipolar disorder being recognised sooner, with 50% selecting this. However, the second most frequently cited barrier was the fact that they had been misdiagnosed with the wrong disorder (44%), followed by three options related to GPs' lack of knowledge, assessment skills and time (30-37%). Similar questions were asked in the DBSA survey, although in this case the highest number of respondents considered that professionals' lack of understanding was a barrier (Hirschfeld *et al.*, 2003). It may be that in the current study there were a number of options relating to the knowledge and skills of professionals, so this overall theme was diluted across these responses.

Notably, a relatively high number of respondents (24%) provided free text answers to this question, most of which related to flaws in the approach of professionals. A number of people also commented on concerns about the judgement of others (including professionals) and fear of the stigma associated with mental health problems as reasons why they did not seek help or report all their symptoms. Others suggested that a previous misdiagnosis had led them to mistrust the expertise of professionals, a concern also reported by Inder and colleagues (2010).

It seems that service users consider that many of the barriers to receiving appropriate help relate to the knowledge and approach of professionals, particularly GPs. However, their

acknowledgement of lacking insight into their own symptoms cannot be ignored. It could be that concerns expressed about stigma and society's lack of understanding are relevant here. A general greater awareness of mental health problems, such as bipolar disorder, may help individuals and their friends and families to be more alert to, and comfortable reporting, the range of bipolar symptoms.

5.2.5 Aim d) Service user views on overcoming issues: early indicators, service improvements and assessment questions

Participants were asked about pre-diagnosis indicators or warning signs of hypomania or mania, as well as pre-diagnosis features of depression and additional lifetime risk factors, in terms of whether these would be useful for someone carrying out a mental health assessment, or screening for possible bipolar disorder, to ask about. Regarding manic/hypomanic warning signs, disturbed or reduced sleep was most frequently selected (75%). Racing thoughts, many ideas/increased creativity and increased productivity were the next three highest rated indicators (56-62%), suggesting a general picture of increased activity and efficiency. Disturbed sleep was notably also a highly rated reason why people first sought help (see Section 5.2.2). This could therefore be a key thing for GPs to ask about, as it is likely that people would have fewer reservations about reporting it, unlike some of the other potential symptoms which would be harder to ask about or to objectively measure. Consistent with this, erratic sleeping was reported in the Hirschfeld *et al.* (2003) survey as the symptom that service users were most prepared to disclose to a doctor.

With regards to depression, the most frequently experienced feature was 'lethargy and exhaustion' (73%) followed by 'intense and debilitating depression' (70%) and suicidal ideation or attempts (65%). This suggests that as well as being generally exhausting, the depression experienced is severe and devastating. It is difficult to consider how these features may be distinguished from symptoms of unipolar depression. However, research suggests that bipolar depression is associated with more functional impairment than unipolar depression (Shaffer *et al.*, 2010), so if patients in primary care seem to be severely depressed in a way which disables them in most areas of their life, it could be appropriate to screen these people for other mood states.

Participants were then asked about their experience of various lifetime risk factors. Difficult life events were most frequently experienced, selected by over three quarters of respondents. This risk factor was fairly inclusive, as what constituted a 'difficult life event' was not explicitly defined. However, service users' high rating of an external event as a factor contributes to more psychosocial explanations of bipolar disorder, or at least indicates that they play an important part, possibly consistent with a diathesis-stress type model (Alloy *et al.*, 2005). A family history of mental health problems was a risk factor for 63% of participants and depression in the immediate family (parents and siblings) applied to 54%. This is consistent with research literature reporting on genetic links of mood disturbance (Goodwin & Jamison, 2007) although in this study it cannot be established whether these links are hereditary or related to the environmental impact of having family members with mental health problems. Either way, it seems that family mental health histories may also be useful things to enquire about when screening for bipolar disorder, as they apply to a large percentage of respondents.

In terms of age of onset, participants first experienced depressed mood symptoms at a mean age of 17.7 years, suggesting that early onset of mood symptoms is also relevant in this sample and might be a useful thing to be explored during assessment. An onset of depression prior to age 21 has been previously reported to be indicative of bipolar disorder (Angst *et al.*, 2010).

Participants were asked to rate how well they thought different professionals and the public understood bipolar disorder. People considered the understanding of specialist mental health professionals to be reasonable, rating them between 6.7 and 7.6 out of ten; however, GPs were rated lower than this, at 5.2, suggesting less satisfaction with their level of understanding. Respondents thought that service users themselves had the greatest understanding, indicating that service users could be a valuable resource to service providers as experts by experience. The general public did not receive a favourable rating (just 2.4/10), which is consistent with the themes of stigma and discrimination evident elsewhere in the survey, and also indicates that the recent media coverage of bipolar disorder (Chan & Sireling, 2010) may not, in reality, have succeeded in promoting public awareness of bipolar disorder.

This theme continued into the question on possible ways of improving the assessment and identification of bipolar disorder. Over three quarters of participants chose the highest rated response: that society needed to be more educated on mental health issues. The idea that GPs also needed more training on bipolar disorder was the second most highly rated (74%), and another popular idea was that already trained mental health professionals should carry out such

assessments in primary care (68%). These ideas support the implementation of initiatives like the bipolar management education programmes recently carried out with primary care staff in France (Hantouche *et al.*, 2009) which were found to be effective (Rouillon *et al.*, 2011).

Longer primary care assessment slots and more thorough assessments prior to being medicated were also both highly endorsed options, and ones which were elaborated on in the qualitative responses, where a number of people suggested that antidepressants were prescribed too casually. Service users also felt that they themselves should be involved in the training of professionals. Elsewhere in the survey, qualitative responses indicated that service users also feel that they benefit personally from being 'professional service users', so this could be a training strategy which is beneficial for both users (in terms of their sense of purpose and self-confidence) and services (in terms of gaining valuable insights only obtainable by consulting a service user).

The majority of participants (almost three quarters) thought that all of the questions suggested by the focus group would be helpful to ask. Enquiring about the impact of mood changes on everyday life seemed to be the most popular choice, with 89% endorsing this. In terms of qualitative responses, people thought that a more open, exploratory and interested approach would elicit more honest and genuine responses, rather than a list of 'tick-boxes'. This contrasts with findings that professionals should ask targeted rather than general questions reported by Lewis and Hoofnagle (2005). It may be that a detailed, non-directive approach would be most appropriate if there is the time to elaborate, but the constraints in current primary care practice (Smith *et al.*, 2010b) make it unlikely that GPs would have the time to carry out this type of assessment.

In terms of ideas which may be more realistic to implement, participants also emphasised the importance of repeat assessments (e.g. if just a ten minute slot is available, assess over a number of these), asking about mood history and family history of mental health problems, asking patients to complete mood diaries which can be reviewed in follow-up sessions and consulting family members. Assessing mood history, family history and involving family in the assessment process have previously been cited as helpful approaches for identifying bipolar disorder (e.g. Muzina *et al.*, 2007; Swann *et al.*, 2005). People also offered a list of possible specific symptoms and experiences to ask about, and again the manner in which such questions could be asked was considered to be important. As highlighted previously, one key symptom may be disturbed or erratic sleep, with a possibility of patients also keeping a sleep

diary. People also indicated that they were less keen on the use of screening tools, with comparatively few people selecting this as a potential way to improve services (Q17), and qualitative comments indicating that such instruments were no substitute for proper training. However, the literature on screening tools suggests that they are not widely or consistently implemented due to practical and methodological issues (e.g. Miller *et al.*, 2009) not because service users do not favour them.

5.2.6 Aim e) Service user views on the usefulness and impact of a bipolar diagnosis

The vast majority of participants (94%) indicated that they thought that a diagnosis of bipolar disorder was correct for them, suggesting that they identified with it in some sense as a way of explaining their symptoms better than any previous diagnoses.

Overall, more people selected responses relating to why a diagnosis was helpful than why a diagnosis was unhelpful, despite there being equal numbers of predetermined responses listed for each. People were most likely to find their diagnosis helpful as a means of ‘sense-making’ (88% agreed with this), information gaining (83%), and developing insight into the condition in order to manage it effectively (77%). These highly rated reasons of why diagnosis is helpful were consistent with smaller scale qualitative studies which reported that people found that diagnosis facilitated service user understanding and management of their difficulties (Proudfoot *et al.*, 2009; Veseth *et al.*, 2012).

In terms of unhelpfulness of diagnosis, the most frequently selected response (chosen by 66%) related to coping with social stigma, and the third most frequently chosen ‘concern over the reaction of others’ (57%) was also related to this. Qualitative responses to Q24 also indicated that people felt strongly about the existence of stigma and discrimination. A number of people strongly challenged the suggestion that diagnosis was helpful as it could prevent discrimination, and indeed relatively few people endorsed this option (16%). This experience of and concern about discrimination and stigma is a challenge for UK society, especially if legislation such as the Disability Discrimination Act (2005) and the Equality Act (2010) are not being adhered to. In terms of unhelpfulness, many people commented on the media coverage and association of bipolar disorder with celebrity culture as being unhelpful, because, with a few exceptions (notably Stephen Fry), it did nothing to improve public understanding of what having bipolar disorder is really like or to decrease the stigma associated with it. Perceived stigma was also

reported to be a concern in the qualitative study carried out by Michalak and colleagues (2006), as it could detrimentally impact service users' quality of life.

People also frequently selected 'reliance on medication' as unhelpful (58%) and there were a number of qualitative comments where people expressed frustration at this, as well as annoyance at the side effects and the desire to try alternatives, which may be useful for professionals to consider before prescribing psychoactive medication. Related to this was the theme that a diagnosis is only helpful if people get the appropriate follow-up care.

Participants were asked if they would prefer to have a diagnosis of bipolar disorder to explain their experience than no 'label' at all. The majority of people showed a preference for having the diagnosis, with 86% choosing this. In terms of the anti-psychiatry movement and concern about the validity of psychiatric diagnosis, this suggests that people experiencing symptoms associated with bipolar disorder do relate to this medical conceptualisation of the problem. Not only does it add explanation and remove personal 'blame', but the diagnosis helps people to manage their symptoms. However, although some viewed medication as inevitable, many people suggested that they were not keen on the reliance on solely pharmacological interventions. A psychological formulation approach (BPS, 2011a) alongside the diagnosis would be valuable in order to understand how individual biopsychosocial differences may contribute to the aetiology, maintenance and most appropriate interventions for service users whose symptoms are best described under the diagnostic label of bipolar disorder. As Inder *et al.* (2010) emphasise, receiving a diagnosis should be a process of active meaning making, and how service users are treated after their diagnosis is crucial for the best outcomes.

5.2.7 Aim f) Carer perspective

Overall, there were no major differences between answers given by service users and answers given by carers, and most responses, included qualitative responses, followed remarkably similar themes. The similarities in these responses corroborate service user opinion and are valuable as carers are often considered to add objectivity. Carer responses in some cases were slightly more conservative, e.g. mean length of delay from help seeking to diagnosis was reported by carers to be 6.5 years, rather than over ten, and mean number of consultations to a medical professional to be 9.6 instead of over 10. It may be that those service users who had carers to support them who were willing to complete the survey may have faced less difficulties

during the diagnostic process due to having someone to act as an advocate for them. This is particularly likely as over 90% of carers reported knowing the service user before they were diagnosed.

Another slight difference in carer responses related to the nature of the first signs of bipolar: carers considered that irritability and argumentativeness were early indicators more often than service users did. In terms of pre-diagnostic signs of depression, carers rated rejection sensitivity most frequently, whereas for service users this was the fourth most common response. The signs that were selected more frequently by carers were more outwardly observable features that would be directed at other people, as opposed to, for example, racing thoughts or thoughts of suicide, so a bias towards these from an outside observer would be understandable. However, these are still things to consider from the point of view of assessment, particularly with regards to what family members and friends may notice which could be indicative of bipolar disorder.

In terms of their qualitative comments, carers were, understandably, most likely to advocate the involvement of family and carers in the assessment process, and many commented that they often felt overlooked by professionals during both diagnosis and aftercare. Many believed that their involvement from the beginning would have led to better outcomes for the service user involved. This is consistent with the literature which reports that carer views are frequently neglected (Elgie & Morselli, 2007; Foster, 2010).

5.2.8 Summary

Overall, service users considered that the issues raised in the survey were important and many expressed strong and detailed views about their personal experiences and the services they had received. The high volume of qualitative responses also adds weight to the service user views on the importance of these issues. Whilst some comments suggested that people did not always agree with the majority opinion, the vast majority of people suggested that the assessment and diagnosis of bipolar disorder needed to be improved. Respondent feedback on the survey itself (Section 4.7.6) also indicated that people mostly supported the direction of the research and appreciated the opportunity to comment. It is hoped that when people had views which strongly disagreed with ideas implied by the questions being asked, that the anonymous

nature of the survey would have enabled them to freely express these views, as they did in Q24 when challenging the idea that a diagnosis would help to prevent discrimination.

KEY IMPLICATIONS

A number of implications can be elicited from the results of this study. Firstly, the published research literature on the diagnosis of bipolar disorder suggests that delayed diagnosis and misdiagnosis are significant problems. This study contributes to this literature by offering a more service user framed perspective than previous studies and reports, and offering a more up-to-date and in-depth analysis of the problem than has been provided by previous survey studies (Hirschfeld *et al.*, 2003; Lish *et al.*, 1994; Morselli & Elgie, 2003). To the author's knowledge, it was also the first study of its kind based primarily in the UK. Whilst it could be anticipated that progress had been made with the issues highlighted in these studies over the last decade, the results to the current study indicate that in the UK this is not the case and that people are experiencing even longer delays and are more frequently misdiagnosed. Supporting this, a significant negative correlation was found between the length of diagnostic delay and the number of years since diagnosis, suggesting that people diagnosed more recently were likely to have experienced longer delays than those diagnosed longer ago. This adds weight to the suggestion that currently, at least in the UK, the recognition of bipolar disorder is not improving.

5.3.1 Implications for services

The results of this project suggest important implications for professionals and services. The length of delay between help-seeking and diagnosis, the number of reported consultations before bipolar disorder is identified, and the frequency of misdiagnosis indicate that doctors need to improve their practice in this area. In particular, the risks reported by respondents in relation to inappropriate antidepressant use, and the high percentage of survey respondents who reported attempting suicide before they received appropriate help indicates that current practice is not only inadequate, but presents considerable risks for service users. Participants were frequently not happy with the approach, understanding, knowledge and skills of GPs compared to other mental health professionals, or the lack of prioritising of mental health issues in primary care. They considered that GPs need to have more training on mental health

problems generally, and specifically need to improve their strategy for assessing bipolar disorder in patients who appear to present with depression or anxiety, for these issues to be overcome.

At the very least, those that practice in primary care should be familiar with NICE guidance for the treatment of bipolar disorder and should be aware of the potential destabilising effects of antidepressants for those with a bipolar presentation. Accordingly, this study indicates that antidepressant medication should not be prescribed prior to a thorough mental health assessment which has fully considered the needs of the service user and ruled out possible bipolar disorder. It should also be noted that the current trend of rapidly increasing antidepressant use in the UK (Batty, 2011) is concerning in the context of the current study findings.

Whilst it seems that many GPs need better training on bipolar disorder, as 'general' practitioners who are expected to have knowledge of a wide range physical and mental health conditions, it may be inappropriate for them to diagnose mental health conditions such as bipolar disorder which are considered to be 'severe and enduring'. Indeed, they may not be comfortable doing so, especially within the confines of a ten minute consultation. However, it does seem appropriate for GPs to be able to screen for potential bipolar disorder in order to refer on patients they are concerned about for a more in-depth assessment. Currently this does not seem to be happening.

Of course, the waiting lists for secondary care mental health services can be lengthy, and it is possible that GPs may make a decision not to screen for more severe problems or refer on partly due to awareness of strained mental health services and concern about the impact of a long wait on service users. This suggests that in some cases the issues may lie within the structure of services as opposed to the skills of those in primary care.

In relation to Wales specifically, new legislation coming into force during 2012 (Mental Health Measure; National Assembly for Wales, 2011) may assist with some of these problems. One of the aims of the measure is to reduce the long waiting lists for secondary mental health care by introducing separate Primary Care Mental Health Support Services (PCMHSS), which will manage initial mental health assessments and care of people with mild to moderate mental health problems. This is promising for those with undiagnosed bipolar disorder, as the GP would simply be required to identify a mental health problem needing further assessment in the first

instance, before referring the patient on to a PCMHSS worker. This professional would then offer a mental health assessment within 28 days, and a bipolar presentation would hopefully be identified. However, it is currently unclear who these professionals will be, how they will be trained and who will be supervising them. It seems that if more mental health problems will now be assessed and managed in primary care, professionals working in this setting will need to greatly improve their knowledge and understanding of mental health issues.

Similar stepped-care models have already been implemented elsewhere in the UK over the last five years (e.g. Improving Access to Psychological Therapies (IAPT) – England; Increasing Availability of Evidence-based Psychological Therapies in Scotland). However, IAPT, which initially focussed on providing time-limited psychological therapies such as CBT for depression and anxiety, has only recently considered broadening its service provision to include psychological interventions for those with 'severe mental illness' such as bipolar disorder (IAPT, 2012). It is not clear how this will affect the initial identification of bipolar disorder, but training IAPT workers on bipolar disorder may mean that it is more likely to be recognised.

5.3.2 Implications for clinical psychologists

This research could have a number of implications for clinical psychologists specifically. For those working in secondary care mental health teams carrying out assessments or one-to-one therapy with people presenting with depression, remaining alert to all aspects of an individual's mood experiences is important in case their difficulties are more appropriately conceptualised as bipolar disorder. Indeed, as clinical psychologists are trained to carry out in-depth assessment and formulation, they may be well-placed to recognise any less obvious but still problematic mood variations in their clients. Additionally, the need for psychological services in primary care settings has been highlighted in recent years (e.g. IAPT; Layard, 2006), therefore psychologists working with clients in this context could contribute to an earlier recognition of bipolar disorder for some people.

The results of this study could also provide a dilemma for clinical psychologists, who are trained to understand and formulate mental health problems in a holistic and individualised way rather than to rely primarily on a psychiatric diagnosis to guide their approach to treatment (BPS, 2011a). From a psychological perspective, it could be argued that if a person is experiencing mood difficulties, whether the specific label which applies to them is depression or bipolar disorder should not matter when formulating and providing psychological therapy. However, this

project indicates that many people really value their diagnosis of bipolar disorder for a number of reasons and would like to have been diagnosed sooner. There is also the difficulty that an incorrect diagnosis or an absence of a diagnosis of bipolar disorder specifically can cause people more distress in the long run, in terms of inappropriate medications and a lack of a meaningful explanation of what they are experiencing.

For clinical psychologists, it is important to use a person-centred approach to mental health care. Therefore, if having a diagnosis of bipolar disorder is important to individuals understanding of their difficulties, this should be accepted within a biopsychosocial approach to formulation which incorporates the diagnosis. Given the relevance of a diagnosis to meaning making and people's self identity, an important part of psychological work with people diagnosed with bipolar disorder should be to explore how people relate to their diagnosis and what it means for them. Furthermore, clinical psychologists could have a role in making sense of the issues relating to stigma and discrimination experienced by people with bipolar disorder and help empower clients to confront these issues.

5.3.3 Recommendations

A number of recommendations could be derived from the results of this survey, and service users and carers themselves also offered specific ideas for the improvement of services. Whilst major service changes in primary care and more emphasis on mental health would be preferable, the implementation of these may not be achievable, especially in the short term. More practical recommendations could be to alert GPs to certain signs and types of questions which would be helpful to screen for bipolar disorder (see Table 5.1 for a summary of assessment recommendations derived from this study). However, this is not a new idea, as a number of publications have made such recommendations (e.g. Mitchell *et al.*, 2008; Muzina *et al.*, 2007) and it seems that these ideas are not being routinely carried forward, certainly in UK practice. These ideas could instead be incorporated into a training session to be delivered to primary care staff, possibly similar to ideas implemented successfully in France (Rouillon *et al.*, 2011). Involving service users and carers themselves in such training may make it more meaningful to professionals as well as being a useful exercise for service users.

Some service users indicated that screening tools could be helpful, but these were less frequently endorsed than other potential improvements (e.g. more training) and were not

considered to be an adequate substitute for a proper assessment carried out by an understanding and skilled professional. However, failing other possibilities, a bipolar screening questionnaire could still be useful. The literature indicates that currently available questionnaires are not adequate, so a possible strategy might be to involve service users in designing a useful screen. One service user suggested that a kind of mental health flow-chart for service users to complete online would be helpful, with a suggestion that the person should consult their doctor if certain patterns of symptoms or experiences were evident.

Overall there is a message from service users that they would like to be listened to and that they consider themselves to have the best understanding of their condition. Service providers would be wise to collaborate with and take onboard the views of service users when considering how services could be developed. As this study has demonstrated, service users have many insightful ideas about how their care could be improved.

Table 5.1 Key considerations in the assessment of bipolar disorder as specified by service users and carers.

- More detailed assessment should be considered for service users who present with either anxiety or depression
- Assessment should take place over a number of follow-up sessions
- If possible consult family members or friends for their observations, especially regarding irritable, aggressive or overly sensitive behaviour
- Ask about family history of mental health problems and unstable mood
- Mood history should be taken, including depression or mixed moods/extreme mood swings during teenage years – consider asking service user to complete a mood timeline or keep a mood diary over number of weeks
- Ask about a history of significant life events and how the service user has coped with them
- Ask about sleep patterns, consider asking service user to keep a sleep diary
- Ask about productivity, ideas and current future plans
- Be alert to severity of depression and suicidal ideation
- Be alert to service users' lack of insight into manic/hypomanic symptoms, or fear of the consequences of reporting them
- Approach assessments in a conversational and understanding way rather than adopting a tick-box/checklist strategy (where possible given time constraints).

5.3.4 Wider implications

Service users described the general public as having very little understanding of bipolar disorder and, worryingly, many had experienced stigma and discrimination. They felt that the public image presented in the media was very different to the experiences of service users. However, the detrimental impact of the media may depend on how bipolar disorder is portrayed and who by. Documentaries such as 'The Secret Life of the Manic Depressive' presented by Stephen Fry have been considered helpful, so there may need to be more informative programmes such as this to educate the public to counteract the sensationalist news stories on the excessive behaviour of various other celebrities linked with the condition.

As stigma and discrimination can serve to increase social isolation and exacerbate mental health problems (Mental Health Foundation, 2012), it is in the best interests of service users, services and society to address it. The recent Equality Act (2010) makes discrimination against people with mental health problems illegal in respect of access to services and employment, and government policies (e.g. No Health Without Mental Health; DoH, 2011b). Similarly, voluntary sector campaigns (e.g. 'Time to Change': Mind & Rethink Mental Illness, 2008) aim to challenge mental health stereotypes, educate the public and reduce stigma and discrimination. It is therefore hoped that people with bipolar disorder will experience fewer difficulties in the future in these respects, but for the respondents in this study stigma and discrimination remain very pertinent issues.

5.4 METHODOLOGICAL CRITIQUE

5.4.1 Overall strengths

The mixed methods approach adopted for this study intended to capture the qualitative experience and views of service users on the topic of diagnosis, which in the past has been dominated by the agendas of researchers and clinicians. The aim was to use these views to design a survey aimed at a larger audience than purely qualitative methodologies allow, which could be analysed quantitatively. Initially consulting a service user focus group ensured their involvement at the research design stage, which is recommended as best practice and should be prioritised in research relating to mental health services (Hayward & Riddell, 2008; Sheldon & Harding, 2010; Tait & Lester, 2005). The involvement of service users in the design of the

research as well as efforts made to incorporate their views and opinions throughout the survey (by the inclusion of qualitative response options) is therefore a key strength of the study.

However, a mixed methods design could be criticised for not adhering strictly to methodological principles of either qualitative or quantitative design. Accordingly, the researcher aimed to maintain a high level of quality in the research by adhering to guidelines proposed by Elliot *et al.*, (1999) and following thematic analysis guidance outlined by Braun and Clarke (2006). Regarding quality checks (See Section 2.1.5), the researcher aimed to own her own perspective, situate the sample and provide quotes to ground the analysis in examples. Credibility, reliability and coherence checks were also provided in a number of ways. Respondent validation was achieved by asking service users to pilot the survey and to provide feedback on whether it accurately represented the views they presented during the focus group. Participants were all satisfied with the content of the survey. They offered occasional feedback on the wording of questions, which were then altered accordingly. The survey itself was then piloted by eight trainee psychologists, the two project supervisors and two non-psychologists. Inter-rater reliability was conducted by a trainee clinical psychologist who read the focus group transcript and checked this against the results of the thematic analysis for agreement. The themes and sub-themes derived were considered to be valid, although additional suggestions were made which were incorporated into this report. The two project supervisors and one non-psychologist read the report as a whole to check for coherence and resonance.

5.4.2 Focus group critique

Whilst efforts were made to involve service users in the design of the research and for this involvement to be genuine, service user involvement faces many criticisms such as tokenism and lack of representativeness. Indeed, the four service users involved in the focus group were high-functioning and had been diagnosed with bipolar disorder for a number of years. Whilst the voice of experience was valuable, and their years of reflection on their situation contributed greatly to the research, it is possible that this was not representative of those who had been diagnosed more recently, or those who were struggling more with managing the condition, especially considering that two of the participants were very used to being asked their views as 'expert' service users in other settings. Additionally, the focus group members all accessed services in Wales, yet the vast majority of survey respondents were based in England, so it is

possible that the experiences of focus group members were not wholly representative of other areas of the UK.

Carers' views were also not represented during the focus group stage. Although the original intention of the researcher was to include both service users and carers in the focus group, recruiting carers for this phase of the project proved problematic. As participants were recruited on the researcher's behalf via Bipolar UK support groups, which were most highly attended by service users, it is possible that the message did not filter through to carers, or that they were less keen or able to take part for other reasons. Unfortunately, this stage of the project represents another example of where carer views have not been incorporated. This could have affected the focus of the survey.

5.4.3 Survey critique

This study successfully used a web-based survey to collect data from a modest sample of respondents recruited via the charity Bipolar UK within a two month time period. These results demonstrate the utility of the internet in gathering data from a population diagnosed with bipolar disorder which would otherwise have been difficult to access in large numbers (Wright, 2005). Additionally, the anonymous nature of the survey and the fact that participants were not traceable by the researcher allowed them to respond to questions honestly and to freely express their opinions without concern about giving socially desirable answers. The strong views expressed as part the qualitative responses to survey questions suggests that participants were able to do this freely without concern about information being accessed by professionals with whom they had had contact or other people that they knew.

Many results were similar to those reported in previous survey studies which asked questions about diagnosis (Hirschfeld et al., 2003; Morselli & Elgie, 2003) as well as other studies which reported delays in diagnosis (Berk *et al.*, 2007), suggesting that the experiences of these participants are representative of other people diagnosed with bipolar disorder. This survey contributes further to this research by providing a more detailed analysis of people's experiences as well as including their views on how service improvements could be made.

However, internet surveys also face a number of criticisms. Firstly, it is difficult to ascertain the size of sampling frame for internet based research, as membership of particular invited groups is not often known. Although the main publicity method for the current study was via an email

sent by Bipolar UK to 2000 of its members, it is impossible to know how many people came across the web-links, as they could have been passed on to others via social networking sites and other communication methods. Whilst it was important for the survey to be accessed by those it was directed at, the researcher was also keen to reach as many potential participants as possible, so this was not actively discouraged.

A flaw of internet based research is considered to be a systematic sampling bias: only certain people will complete online surveys. Reliance on a web-based method may have led to an over-representation of more privileged social groups (Heiervang & Goodman, 2011). Although internet use is increasingly commonplace, some people, e.g. generations who may be less comfortable with using the internet, and those who do not have convenient internet access, may be automatically excluded due to these factors. However, as internet use increasingly becomes a part of everyday life for the vast majority of people, the effects of this sampling bias are likely to be continuously decreasing. Additionally, Chang *et al.* (2008) compared a web survey sample of people with bipolar disorder with in-person and telephone samples and found the web sample to be adequately representative of people with bipolar disorder.

Another problem is that the characteristics of those who decide not to take part are unknown. Those who did not chose to complete the survey may represent an important demographic who were not interested in the research as it was not applicable to them, or who may have struggled to focus on an in-depth survey for reasons which may be related to their illness. Indeed, some of the qualitative comments indicate that people had struggled when affected by symptoms of bipolar at the time of survey completion (e.g. racing thoughts). This may lead to difficulties when it comes to generalising the results. In addition to this issue, it is also not known how representative members of Bipolar UK are of the general population with bipolar disorder.

Similarly, web surveys are also vulnerable to a self-selection bias. It was clear from the publicity and information page that the survey was about diagnosis, but also that service user views were needed. It could be that this attracted those that felt particularly strongly about these issues, whereas those who had faced fewer difficulties may not have felt the need to contribute. This could account for the number of quite extreme responses gained in the survey. (e.g. the diagnostic delay reported is even greater than that found in the pre-existing literature, and the number of medical consultations before receiving a diagnosis is surprisingly high). One possible way of overcoming this difficulty could have been to advertise the survey to people with bipolar disorder but to be less specific about the topic in the information material. Yet this approach

would have meant not fully informing participants of the nature of the survey, which is an ethically more questionable approach. However, considering the (very approximate) number of people that the sample was pooled from (2000), the response rate of 327 in total was well over 15%, which could be considered to be reasonable for surveys of this nature (Hamilton, 2009). This suggests that a sizable proportion of people were keen to express their views on the topic, and given that these issues have been previously reported, it is likely that delayed diagnosis is an issue for a large number of people with bipolar disorder. Equally, if people felt strongly that it was not an issue, there were many opportunities to express this view in both the predefined response options and the free-text boxes throughout the survey.

In particular, internet based research aimed at people with mental health diagnoses is problematic as clinicians cannot validate the self-reported diagnosis (Chang *et al.*, 2008). By virtue of recruiting solely through the charity Bipolar UK, who sent members a private email with the survey internet links, it was hoped that the vast majority of participants would be genuine service users. Additionally, in the service user version of the survey, there were three questions which mapped onto DSM-IV (APA, 2000) diagnostic criteria for bipolar disorder. The survey questions, being specifically about the process of diagnosis itself, would be unanswerable by anyone who hadn't been diagnosed with bipolar disorder, so even if such people began the survey for some reason, they may well have lost interest very quickly or realised that the survey was not directed at them and discontinued (only completed surveys, requiring people to 'submit' after the final question, were recorded). For these reasons it is considered that that survey respondents were likely to be genuine service users with a diagnosis of bipolar disorder. Although all information was self-reported, the inclusion of a carer survey with overall results very similar to those gathered from service users also corroborates service user reports. The retrospective nature of the survey, however, also means that results should be interpreted with caution due to the flaws of human memory. Indeed, some respondents commented that they had struggled to remember their age during different experiences and had provided an estimate.

One consideration regarding the focus of this research is that diagnosis is a socially constructed concept, and not necessarily an objective reality. By designing a project about diagnosis, beginning with recruiting focus group members and asking them to discuss their views on diagnosis, the assumption has been made that there is a valid and diagnosable condition labelled 'bipolar disorder', making it harder for service users to challenge this view if they wished to. Question 24 of the survey, which asked people about the value they attached to their diagnosis and whether they would prefer it to an alternative explanation, attempted to explore

service user views on the concept of diagnosis itself. Whilst some valuable responses were provided to these questions, the inclusion of such questions within a survey which also asked about more concrete topics such as 'age of diagnosis' and 'barriers to diagnosis' may not have been the most meaningful way to exploring people's views on the concept of diagnosis itself. However, for the purposes of this study, it does seem that people relate to their diagnosis in a number of ways which are helpful to them. Future research could explore service user perspectives on the validity of the diagnosis of bipolar disorder itself. As one participant commented, 'we also need research on how labels have been invented and why'.

A related concern is the meaning that participants could have made of individual questions. Some inconsistencies in responses suggest that a few questions may have been interpreted in slightly different ways. The most notable of these was for responses to questions 15a and 15b, where people reported being misdiagnosed a mean of 4.3 times, but in the following question a mean of two different misdiagnoses were reported, an inconsistency which may have arisen out of question interpretation. Answers to 15a may have been responding to the number of occasions someone was misdiagnosed, even if a previous 'misdiagnosis' was upheld or re-diagnosed more than once.

Despite the survey questions being designed with the help of service users and piloted on a number of different people, it is possible that the length and the extent of detail in the survey could have become tiring for some service users as indicated by this service user's comment: 'It was hard to read with racing thoughts but I did my best!'

With a survey designed from scratch it would be unlikely that responses to every question would accurately represent the views and experiences of all 327 respondents. Free text boxes were provided throughout to enable participants to contribute any alternative comments or to voice disagreement. As indicated by the qualitative feedback offered in response to Q25, (see Appendix L), the vast majority of comments on the questions and the nature of the survey were very positive.

As with the focus group, it proved harder to recruit carers in similar numbers to service users as indicated by the lower response rate. This may have been partly due to the ratio of service user to carer members of Bipolar UK. It may also be that carers are a fairly difficult to access population, hence them often being neglected in research. The current study did make every

attempt to include carers' views and opinions within the research, given the recruitment strategies available.

5.5 FUTURE RESEARCH

The current research highlighted several possible areas for future investigation. A next step in relation to this study could be to feed the survey results back to GPs and other professionals, to gain their perspective on the results, whether they think that they are accurate, why they think difficulties exist and what can be done to make improvements. This could be carried out using a survey format, in-depth focus group interviews, or both. Data in the current study could also be analysed further, particularly with regard to the extensive qualitative data which has been summarised for the purposes of this report.

Participants in the current study were thought to represent a fairly well functioning demographic of people with bipolar disorder, especially given the online nature of the research. Gaining information about the experiences of those who were less able to access the internet or articulate themselves in this format would be valuable and more representative of the UK population with bipolar disorder. A possible way in which to do this would be to access patients via NHS community mental health teams, where they could either access the survey with the assistance of a mental health professional or complete a pen and paper version. However, this method of recruitment may remove some of the benefits of participating completely anonymously, and participants may feel constrained in what they are able to say in this environment.

Additionally regarding demographics, it would be useful to compare experiences of participants based in Wales, Scotland, Northern Ireland and England, to find out if there were any differences. As the vast majority of respondents were based in England, the numbers based in other areas were not large enough to adequately compare them in the current study. Equally, for a study of this nature, recruiting a larger sample size would be beneficial, so setting out to gain a larger number of respondents, possibly by recruiting via a number of different organisations, would mean that the results could be more appropriately generalised and comparisons between different groups would be more meaningful.

The survey asked about a large range of things in relation to the diagnosis of bipolar disorder and gained an overview of service user experiences and views on these topics. However, now

that an understanding of service user views on the issues has been gained, future research could focus on more in depth investigations of each area (such as the meaning and value of diagnosis itself) potentially using qualitative interviews. Other issues which arose from the survey could also be investigated further. Some respondents expressed negative views on their treatment and care after diagnosis. However, no questions in the survey explicitly explored this further. This is an important issue, as if people are still not getting appropriate care following their diagnosis, the diagnosis becomes less useful to service users.

Due to the similarity of carers' responses to those provided by service users, and the relatively few carers who completed the survey, the results of the carer survey were included where relevant but not explicitly focused on. The lack of carers at the focus group stage of the project also meant that their views were not represented in the design of the survey which, as a result, was very much aimed at service users' views, or carers' views on service user experiences, rather than on their own experience as a carer. As it is frequently reported that carers are overlooked, future research could just focus on recruiting carers and considering the specific challenges that they faced in the process of the person they care for being diagnosed with bipolar disorder.

Future initiatives could also involve a service user group in designing a screening tool that they would find user-friendly, contributing ideas to an assessment protocol, or helping to develop and implement a bipolar training programme for primary care staff. Research could then focus on evaluating any changes or improvements occurring as a result of such developments.

5.6 CONCLUSION

This research aimed to explore a service user and carer perspective on the issues faced during the process of being diagnosed with bipolar disorder in a UK-based study. It has shown that service user and carer perspectives were broadly consistent with the existing literature which posits that delayed diagnosis, misdiagnosis and the prescription of inappropriate medication are significant problems. It also explored service user and carer explanations and ideas for possible solutions. This study suggests that primary care services need to improve their strategy when it comes to assessing and recognising bipolar disorder, and that GPs would benefit from additional training, which service users themselves could be involved in. Service users also considered that lack of public understanding was a major contributor to bipolar disorder not

being identified. A major strength of this research was the inclusion of service user views at all stages of the project. However findings should be interpreted cautiously, bearing in mind the sampling limitations of web survey based research. Overall, this research indicates that service users have strong views on the assessment and diagnosis of bipolar disorder. Future research could investigate these views further and consider how they could be practically incorporated into clinical practice.

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LIST OF APPENDICES

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Appendix A – Literature search summary table

Appendix A – Literature search summary table

The following table outlines the searches carried out as part of the literature review.

- Searches were carried out in sections, as indicated by blue text.
- Searches with a large number of hits (Column D) were refined further before abstracts were searched in detail. However, some of these initial searches are included in the greyed out rows to provide context for the specificity of later searches.
- When abstracts were searched in detail, the total number of articles selected as relevant to the current project is indicated in Column E.
- As searches were carried out in order (Column A) due to overlap later searches had less relevant hits due to the removal of duplicates.

The following criteria applied to all searches:

Refined by: Subject Areas = (PSYCHIATRY OR PSYCHOLOGY OR BEHAVIORAL SCIENCES) AND Languages = (ENGLISH)
Time span = 1980-2012. Some searches were also refined by Type = REVIEW PAPER.

(+ in Column B indicates all variations of word – as described fully in Column C)

A. Search number order	B. Summary	C. Search description	D. Hits	E. Relevant articles
Bipolar and diagnosis				
	Title: bipolar+, diagnosis+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identifi* OR misidentifi* OR unidentified* OR recogni* OR unrecognized* OR discover* OR undiscover* OR classif*)	1,104	
1	Title: bipolar+, diagnosis+ Type: Review paper	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identifi* OR misidentifi* OR unidentified* OR recogni* OR unrecognized* OR discover* OR undiscover* OR classif*) Refined by: Document Type=(REVIEW)	175	65

Bipolar diagnosis issues

	Title: bipolar+, diagnosis+ Topic: issues+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identif* OR misidentif* OR unidentified* OR recogni* OR unrecognized* OR discover* OR undiscover* OR classific*) AND Topic=(barrier* OR issue* OR difficult* OR controversies* OR argument OR debat* OR problem*)	187	
2	Title: bipolar+, diagnosis+, issues+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identif* OR misidentif* OR unidentified* OR recogni* OR unrecognized* OR discover* OR undiscover* OR classific*) AND Title=(barrier* OR issue* OR difficult* OR controversies* OR argument OR debat* OR problem*)	54	3
	Title: bipolar+, antidepressant	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(antidepressant*)	386	
3	Title: bipolar+, antidepressant Type: review article	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(antidepressant*) Refined by: Document Type=(REVIEW)	40	20
4	Title: bipolar+, antidepressant Topic: 'switch' (e.g. to mania)	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(antidepressant*) AND Topic=(switch)	84	17
5	Title: bipolar+ Topic: underdiagnosis	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Topic=(under-diagnos*)	17	11
6	Title: bipolar+ Topic: delayed diagnosis	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Topic=(delayed-diagnos*)	17	9
7	Title: bipolar+ Topic: over diagnosis	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Topic=(over-diagnos*)	9	2

8	Title: bipolar+, misdiagnosis	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(misdiagnos*)	44	13
9	Title: bipolar+, comorbidity Type: Review	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(comorbid*) Refined by: Document Type=(REVIEW)	65	11
10	Title: bipolar+, stigma	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(stigma*)	15	5
Screening tools				
	Title: bipolar+ questionnaires+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(screen* OR questionnaire* OR measure* OR assessment* OR tool*)	563	
	Title: bipolar+ questionnaires+ Topic: diagnosis	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(screen* OR questionnaire* OR measure* OR assessment* OR tool*) AND Topic (diagnos*)	332	
11	Title: bipolar+ questionnaires+ Topic: review articles	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(screen* OR questionnaire* OR measure* OR assessment* OR tool*) Refined by: Document Type=(REVIEW)	48	10
Service user perspectives				
12	Title : SU+ perspectives+ bipolar+ diagnosis+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identif* OR misidentif* OR unidentif* OR recogni* OR unrecogni* OR discover* OR undiscover* OR classific*) AND Title=(service-user* OR carer* OR patient* OR client*) AND Title=(perspective* OR opinion* OR view* OR idea* OR experience*)	8	2

13	Title : bipolar+ service user+ perspective+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(service-user* OR carer* OR patient* OR client*) AND Title=(perspective* OR opinion* OR view* OR idea* OR experience*)	34	6
14	Title: bipolar+, diagnosis+ Topic: SU+ perspectives+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identif* OR misidentif* OR unidentif* OR recogni* OR unrecogni* OR discover* OR undiscover* OR classif*) AND Title=(service-user* OR carer* OR patient* OR client*) AND Title=(perspective* OR opinion* OR view* OR idea* OR experience*)	66	9
15	Title: SU+ perspectives+ Topic: bipolar+ diagnosis+	Topic=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Topic=(diagnos* OR misdiagnos* OR undiagnos* OR detect* OR undetect* OR identif* OR misidentif* OR unidentif* OR recogni* OR unrecogni* OR discover* OR undiscover* OR classif*) AND Title=(service-user* OR carer* OR patient* OR client*) AND Title=(perspective* OR opinion* OR view* OR idea* OR experience*)	73	2
Pre-diagnosis indicators				
	Title: bipolar+ indicators+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(trait* OR clue* OR characteristic* OR risk* OR sign* OR feature* OR precursor* OR warning-sign* OR indicat*)	1322	
	Title: bipolar+ indicators+ Topic: Diagnosis	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(trait* OR clue* OR characteristic* OR risk* OR sign* OR feature* OR precursor* OR warning-sign* OR indicat*) AND Topic=(diagnos*)	651	
	Title: bipolar+ indicators+ Topic: Development (e.g. of bipolar disorder)	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(trait* OR clue* OR characteristic* OR risk* OR sign* OR feature* OR precursor* OR warning-sign* OR indicat*) AND Topic=(develop*)	196	
16	Title: bipolar+ indicators+ Type: Review paper	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(trait* OR clue* OR characteristic* OR risk* OR sign* OR feature* OR precursor* OR warning-sign* OR indicat*)	107	15

		Refined by: Document Type=(REVIEW)		
Current services				
	Title: bipolar+ Topic: primary care+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Topic=(primary care OR general practi*)	512	
17	Title: bipolar+, primary care+	Title=(bipolar* OR manic-depression OR atypical-depression OR mania* OR hypomania* cyclothymia* OR mood-disorder) AND Title=(primary care OR general practi*)	57	15

Appendix B – Focus group transcript extract

Appendix B – Focus group transcript extract

Focus Group 27th Oct 2011

F. So how about for people who haven't been diagnosed, who know something's up but they don't know what to do. Who should they go to for help?

Siwan: Before they know anything?

Jacob: Go to their GPs definitely. Or they should be able to.

David: Yep that would be my response; you just need to find the right one because most of them are crap!

Elanor: That's when I think it should be assessed. The GP says to you 'I just need clarification on how you're feeling at the moment. I want you to go and see somebody and spend a day with them, or an hour with them, or whatever and somebody just talk to you'. But they don't do that.

Siwan: Yep that would be nice. Greater overall recognition, just that if people talked about it more, like people would talk about having a headache, they would go to their GP a lot earlier. Then it gets picked up earlier.

Jacob: At my GP's if you're not offered an appointment for 48hours you could instead have an appointment with the nurse – they're so well qualified these days.

David: One group practice, I've forgotten which one, every Friday they have 'mad day'...at the very least the CPN will come in, often the clinical psychologist. Every Friday, if there's anything that's vaguely mental health-y, there's someone to see them, in addition to regular bookings, they can just say, 'tell you what, Dr so-and-so is in on Friday, they're really good, do you wanna go see them?' And that would be helpful, if you could get really quick access to something.

Elanor: Bit like citizen's advice!

Siwan: Even the practice nurses need more mental health training, to make them more effective, because they're easier to access than the GP, usually, I think.

David: Yes.

F. So it sounds like you think this needs to happen in Primary Care?

David: Yes. It really needs to be increased in Primary Care. They've separated it for way too long from physical illness but the two are just inseparable. And that's just ignoring the fact that many physical problems will always have a mental aspect afterwards, even if there wasn't one before. So it really needs to have its profile raised with regard to recognition and importance.

F. What aspects of bipolar disorder do you think are the most likely to encourage people to seek help?

Siwan: I guess the severe depression ... Very depressed, they feel so absolutely awful that they want to do something about it. And maybe if they're high, but maybe they feel so good they're less likely to access help. So we need to encourage them to access help if they are very high.

F. How might you encourage people to access help if they were high?

Siwan: I think their families and friends have got to be educated about it, to recognise the signs and symptoms, and lead their loved one, or whoever, in the right direction.

David: In the grand scheme of things, it would mean educating society better as a whole.

Jacob: When I was on my first manic high, I was stacking the shelves at Tesco's for three months, I wasn't even working there, they asked to see my national insurance card in the end. My mum was seeing a psychiatrist for depression, and so he had already diagnosed me with bipolar. My parents really encouraged me, and my sister encouraged me to go to the doctor. I don't think they really knew very much about bipolar, but the love they have for you, they pick it up anyway. They could have told you all about what was going on, even if I didn't know myself.

David: That happened with me actually too. When I had to retire from the police, it was in about 2000 ... my wife arranged for me to go see a psychiatrist. So that was her recognising that they weren't normal swings of behaviour, and that I really wasn't right. And she recognised it. So she did encourage me to go. Not knowing what it was then.

Elanor: I agree with ... about the depression side I think people would go and seek help if you're low, because when I'm on a high, anyway, like I said before, I don't think there's anything wrong, I always think I'm fine.

David: Yes!

Siwan: You think you're fantastic, don't you.

Elanor: I absolutely love it. I have to notice the warning signs before I get to that stage.

Jacob: The last thing you want to do is go to the doctors! You're drinking all day...

Elanor: So yeah it's hard, to go and get treatment then. It's my husband that then notices, and rings, and insists, and shouts, and speaks to the GP. And then the home treatment team come up.

David: You do find that most people are wrong, when you're on a bit of a high as well.

Elanor: That's a problem I have, yeah *(laughter)*.

F. So are there any other aspects of bipolar disorder which might encourage people to seek help initially?

Jacob: Running out of money, because you spend a lot of money on a high ... you seek help to try and get your money back in order. That's one I can think of anyway...

Elanor: My warning sign is I don't sleep. And if I don't sleep for too long, that's it, I'm high. So I would go straight away now if I had two nights without sleep, no sleeping tablets in the house, that minute I would say, I gotta go and get some sleeping tablets, because I know I will go high if I don't. So I will personally go and get them straight away because I know I would go up otherwise.

F. So do you think that the lack of sleep is something that people generally might notice?

Siwan: It might be, yes.

Elanor: That's what I noticed.

Siwan: Everything's out of perspective, if you haven't slept properly, everything's out of kilter.

F. So what else did you notice before you were diagnosed? Any signs that something was not quite right?

Siwan: Well just the depression really, in the first case. Very very severe depression. You can't do anything. You can't sleep, you can't eat, you can't concentrate – you can't do anything. You just exist.

Elanor: See I don't know much about that. Because mine involves coming after highs, or I get psychotic, you know, where I see things that are not there and all of that. And the voices and things, and the voices are what really frightens me. Touch wood I haven't had that for a few years now. But I think if I had anything like that, I would notice that not being normal. Whereas when I had it all those years ago, I just thought, I'm special! But now I hope that I know that's not right. The trees don't talk to you.

F. So that would be a warning sign...

Siwan: Getting psychotic symptoms, yes. I luckily don't get them so ... not for me.

Jacob: When I first had a high, I was off the scale. If you had 0 to 100, I was like 98 or something. So I was completely off the scale, originally, and I had no idea. Now, I'd probably recognise the symptoms, notice the triggers, and know when to get help.

F. So it sounds like having a diagnosis has been really helpful in terms of managing your symptoms?

David: I agree, if I knew then what I know now, I'd probably still have a career, I'm mean my previous one, just in terms of recognising things early, how to deal with them, maybe looking for a different job within the job, that kind of thing. So in that respect having a diagnosis, having learnt about it, is very helpful, but without that diagnosis...

Siwan: Yes, I agree.

Jacob: The more you know about it, the less likely you are to relapse I think. If I'd have known after the first episode what I knew after I'd had the second episode, I probably wouldn't have had the second episode.

Siwan: With a diagnosis, certainly in my case, psychiatrists point me in the direction of help. For example, he put me in contact with the bipolar research network, and I was a participant and I found that very useful, to actually reflect on my situation.

Appendix C – Survey

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Service User Views and Experiences of Diagnosis In Bipolar Disorder

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Thank you! Please begin the survey....

About You
<p>2. Are you male or female?</p> <p><input type="radio"/> Male</p> <p><input type="radio"/> Female</p>
<p>3. How old are you in years?</p> <p><input type="text" value="Select an answer"/></p>
<p>4. Are you currently working? Please indicate which of the following best describes your situation at the moment.</p> <p><input type="radio"/> Employed full-time</p> <p><input type="radio"/> Employed part-time</p> <p><input type="radio"/> Self-employed</p> <p><input type="radio"/> Housewife/husband</p> <p><input type="radio"/> Doing voluntary work</p> <p><input type="radio"/> Student</p> <p><input type="radio"/> Unemployed</p> <p><input type="radio"/> Retired</p>
<p>5. Are you currently in a relationship? Please indicate which of the following best describes your situation at the moment.</p> <p><input type="radio"/> Single</p> <p><input type="radio"/> Dating/In a relationship but not living together</p> <p><input type="radio"/> Cohabiting</p> <p><input type="radio"/> Married</p> <p><input type="radio"/> Separated</p> <p><input type="radio"/> Divorced</p> <p><input type="radio"/> Widowed</p>
<p>6. What do you consider is your ethnic group?</p> <p><input type="radio"/> White British - English</p> <p><input type="radio"/> White British - Scottish</p> <p><input type="radio"/> White British - Welsh</p> <p><input type="radio"/> Other White British</p> <p><input type="radio"/> White Irish</p> <p><input type="radio"/> Any other White background</p> <p><input type="radio"/> Mixed - White & Black Caribbean</p> <p><input type="radio"/> Mixed - White & Black African</p> <p><input type="radio"/> Mixed - White & Asian</p> <p><input type="radio"/> Any other mixed background</p>

- ☐ Asian - Indian
- ☐ Asian - Pakistani
- ☐ Asian - Bangladeshi
- ☐ Asian - Chinese
- ☐ Any other Asian background
- ☐ Black - Caribbean
- ☐ Black - African
- ☐ Any other Black background
- ☐ Any other background - please specify

7. Where do you currently live/access healthcare services?

- ☐ United Kingdom or Ireland
- ☐ Europe (Except UK)
- ☐ North America
- ☐ South America
- ☐ Africa
- ☐ Asia
- ☐ Australia

a. If you live in the UK or Ireland, please specify:

- ☐ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland
- ☐ Ireland

8. Have you ever experienced a period of extremely high/euphoric mood which has interfered with the way you usually live your life,and lasted as long as a week, or ended up in you needing to go to hospital?

☐ Yes ☐ No

a. Have you ever experienced a period of very high mood which is characteristically different to your usual mood, and lasts at least four days, as well as a period of very low/depressed mood at another time?

☐ Yes ☐ No

b. Have you ever experienced a period of very or extremely high mood lasting less than four days, or a time when you've felt both extremely high and extremely depressed during the same time period... as well as a period of very low/depressed mood at another time?

☐ Yes ☐ No

Before you were diagnosed...

9. Looking back to the time **before you were diagnosed**, what is your best estimate of how old you were when you first showed any signs of having bipolar disorder?

(please indicate your age in years from the drop down menu)

Select an answer ▼

Were these early signs most similar/related to:

- ☐ Mania/High mood
- ☐ Hypomania (less extreme mania)
- ☐ Depression/Low mood
- ☐ A mix of high and low moods/extreme mood swings
- ☐ Other (please specify):

10. What is your best estimate of how old you were when you **first experienced symptoms of depression?**

(please indicate your age in years from the drop down menu)

Select an answer ▼

11. What is your best estimate of how old you were when you **first experienced symptoms of **mania** or **unusually high mood**?**

(please indicate your age in years from the drop down menu)

Select an answer ▼

12. Before you were diagnosed, how old were you when you **first tried to get help for symptoms which you thought at the time, or now think looking back, were related to bipolar disorder?**

(please indicate your age in years from the drop down menu)

Select an answer ▼

a. Who did you **first go to for help with bipolar symptoms?**

- ☐ General Practitioner(GP)/family doctor
- ☐ Psychiatrist
- ☐ Clinical Psychologist
- ☐ Community Nurse
- ☐ Any other health care professional
- ☐ Friend
- ☐ Partner
- ☐ Family member
- ☐ Boss/Line Manager/Supervisor at work
- ☐ Colleague
- ☐ Teacher/Tutor/Lecturer
- ☐ Religious leader
- ☐ Charity - e.g. MDF the Bipolar Organisation/The Samaritans
- ☐ Helpline
- ☐ I didn't voluntarily seek help from anybody
- ☐ Other (please specify):

b. What aspect of bipolar disorder were you experiencing when you first tried to get help?

- ☐ Mania/High mood
☐ Hypomania (less extreme mania)
☐ Depression/Low mood
☐ A mix of high and low moods/extreme mood swings
☐ Other (please specify):

c. Which of the following do you think were factors in you eventually seeking/getting help and getting a diagnosis of bipolar disorder?

(select all that apply)

- ☐ Friends and/or family suggested you should get help
☐ Your employer/work colleagues suggested you should get help
☐ You realised that the symptoms you were experiencing were becoming unmanageable/unbearable
☐ You were spending too much money
☐ You were not sleeping properly
☐ You were at risk of hurting or harming others
☐ You were at risk of hurting or harming yourself
☐ You attempted suicide
☐ There was an emergency situation involving you/someone else being harmed
☐ You were taken into hospital involuntarily (sectioned)
☐ Other (please specify):

13. How old were you when you were first diagnosed with bipolar disorder by a health care professional?
(please indicate your age in years from the drop down menu)

Select an answer ▼

a. What aspects of bipolar disorder were you experiencing when you were first diagnosed?

- ☐ Mania/High mood
☐ Hypomania (less extreme mania)
☐ Depression/Low mood
☐ A mixed of high and low moods/extreme mood swings
☐ Other (please specify):

b. Who diagnosed you with bipolar disorder?

- ☐ GP/Family Doctor
☐ Psychiatrist
☐ Other (please specify):

c. How many times did you consult a doctor (including GPs/family doctors/psychiatrists) with these problems before receiving a diagnosis of bipolar disorder?

Select an answer ▼

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Check Answers & Continue >

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Service User Views and Experiences of Diagnosis In Bipolar Disorder


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Your experience of problems with diagnosis

14. Do you think that you should have received a diagnosis of bipolar disorder/help for bipolar disorder sooner than you did?

☐ Yes ☐ No

Which of these things do you think were a barrier to identifying the problem sooner?

(select all that apply)

- ☐ When I experienced mania or hypomania, I didn't have any insight into there being anything wrong
- ☐ I intentionally didn't report all of my symptoms
- ☐ I didn't want to be diagnosed with a mental health problem
- ☐ I was worried about the consequences of asking for help (e.g. being hospitalised, children being taken away, losing job)
- ☐ When I was depressed I didn't want to ask for help as I was worried about being an inconvenience for people
- ☐ I didn't like going to the doctor's so avoided it
- ☐ I rarely thought of going to the doctor's
- ☐ Communication difficulties between me and my GP
- ☐ Communication difficulties between professionals
- ☐ I was diagnosed with the wrong thing
- ☐ GPs/family doctors don't seem to ask the right questions about the right things
- ☐ Other health/mental health professionals don't seem to ask the right questions about the right things
- ☐ GPs/family doctors do not know enough about bipolar disorder
- ☐ Other health/mental health professionals do not know enough about bipolar disorder
- ☐ GPs/family doctors do not have time to assess people properly
- ☐ Mental health problems are not taken seriously enough in primary care practice
- ☐ Other (please specify):

15. Before you were diagnosed with bipolar disorder, in your opinion, were you ever misdiagnosed with something else?

☐ Yes ☐ No

a. (If you answered 'No' above, please go to Question 16)

If 'Yes', how many times? (Optional)

Select an answer

b. What previous diagnoses were you given?

(Optional) (select all that apply)

- ☐ Depression (Unipolar)
☐ Schizophrenia
☐ Borderline Personality Disorder
☐ Antisocial Personality Disorder
☐ Attention Deficit Hyperactivity Disorder (ADHD)
☐ Asperger's Syndrome
☐ Anxiety Disorder
☐ Conduct Disorder
☐ Alcohol Abuse
☐ Substance Abuse
☐ Other (please specify):

c. (If you **were not** previously diagnosed with depression, please go to Question 16)

If you **were** previously misdiagnosed with depression, were you prescribed antidepressant medication?

(Optional)

☐ Yes ☐ No

d. (If 'No' to 15.c please go to Question 16)

If 'Yes', did you then experience mania/hypomania whilst taking this medication?

(Optional)

☐ Yes ☐ No

e. (If 'No' to 15.d please go to Question 16)

If 'Yes', was this the first time you had experienced mania/hypomania?

(Optional)

☐ Yes ☐ No

16. In your experience, how well do you think the following people generally understand bipolar disorder?

Please indicate how well you think the following understand bipolar by selecting a number between 1 and 10 for each (1 represents 'they have no understanding at all' and 10 represents 'they understand completely')											
	1	2	3	4	5	6	7	8	9	10	Don't know/No experience
a. GPs/family doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Psychiatrists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Clinical Psychologists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Community Psychiatric Nurses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Mental health professionals in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. People with bipolar disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Family and carers of people with bipolar disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

h. The general public

☐☐☐☐☐☐☐☐☐☐☐☐**Overcoming difficulties getting the right help**

17. Thinking about improving assessment and identification of bipolar disorder, which of the following things do you think would have been helpful to you based on your personal experience?

(select all that apply)

- ☐ Assessments of mental health related issues being allocated longer time slots in primary care
- ☐ Professionals who have more time available to be the ones assessing people with mental health related issues instead of GPs/family doctors
- ☐ Professionals who have more training in mental health assessing people with mental health related issues instead of GPs/family doctors
- ☐ Having one person in each primary care practice who has had special training on bipolar disorder and carries out assessments
- ☐ GPs/family doctors having more training on understanding and assessing bipolar disorder
- ☐ Assessments in primary care focusing on people's day-to-day behaviour in order to identify the nature of the problem
- ☐ People being properly and thoroughly assessed before being given any medication
- ☐ Society as a whole being more educated about mental health problems - if people were more aware and understanding, it would be easier for people to seek and get help
- ☐ Screening questionnaires for bipolar being used in primary care
- ☐ Service users and carers being more involved in making decisions about the services they and others get
- ☐ I don't think that any of these things would have been helpful
- ☐ I don't think that services need to be improved
- ☐ Other *(please specify)*:

18. Below is a list of things which are thought to be related to mania and hypomania. Now that you have this diagnosis and know more about it, looking back to **before you were diagnosed**, which of these did you experience to some level and now think could have been an important **warning sign** that you had bipolar disorder?

(select all that apply)

- ☐ I wasn't sleeping properly, and was sleeping a lot less
- ☐ I was much more productive than I usually am, and able to cram loads into each day
- ☐ I was making lots of ambitious plans
- ☐ I was having surreal experiences - seeing and hearing things that weren't really there
- ☐ I seemed to have lots of ideas and felt very creative
- ☐ I was drinking a lot more coffee than usual
- ☐ I was drinking more alcohol than usual
- ☐ I was taking more drugs than usual
- ☐ I was smoking more cigarettes than usual
- ☐ Other people (family/friends/colleagues) seemed to be worried about me
- ☐ Other people (family/friends/colleagues) seemed to be getting annoyed at me

- ☐ I was very irritable, and more likely to start arguments or snap at people
- ☐ I felt more confident and less shy/inhibited than usual
- ☐ I was more talkative and felt more sociable than usual
- ☐ I felt like my mind was racing and I couldn't slow my thoughts down
- ☐ I became much more energetic and active (e.g. sports etc)
- ☐ I started taking risks - driving too fast, trying unusual sports, taking risks at work
- ☐ I seemed to be spending a lot of money
- ☐ I became a lot more interested in sex than usual
- ☐ I wanted to travel around and be out and about more
- ☐ I started wearing more flamboyant and colourful clothes/make-up/hair
- ☐ I didn't notice any warning signs at all
- ☐ Other (please specify):

19. Before you were diagnosed, which of the following features were typical of the times when you were experiencing depressed or low mood?

(select all that apply)

- ☐ None - I didn't experience low mood before I was diagnosed.
- ☐ Feeling very lethargic and exhausted
- ☐ Arms and legs feeling very heavy, like lead
- ☐ Sleeping excessively
- ☐ Overeating and/or gaining weight
- ☐ Intense mood swings
- ☐ Feeling very sensitive to rejection from others
- ☐ Feeling very paranoid
- ☐ Other experiences of seeing/hearing/thinking things that aren't real
- ☐ Feeling agitated and irritable
- ☐ Not responding well to antidepressants - they were either ineffective or my mood became too high
- ☐ Extreme, intense, debilitating depression - like nothing matters
- ☐ Thinking about, planning or attempting suicide
- ☐ When I was depressed I didn't really experience any of these things

20. Research and experience suggests that the following things could be risk factors for people developing bipolar disorder. Please select all those which apply to you.

(select all that apply)

- ☐ A history of mental health problems generally in my family
- ☐ Other people who have had depression in my immediate family (parents and siblings)
- ☐ Other people with bipolar disorder in my immediate family (parents and siblings)
- ☐ High achievements/many achievements
- ☐ Difficult life events
- ☐ Always had mood swings
- ☐ Mood affected by seasonal change
- ☐ Moving house and/or changing jobs a lot
- ☐ Getting into trouble a lot as a teenager

- ☐ The experience of abuse as a child
☐ Alcohol abuse
☐ Smoking/using cannabis
☐ Taking drugs such as amphetamines or cocaine
☐ None of these

21. This question is again thinking about how to improve assessment of bipolar disorder in primary care. A focus group were asked what questions they thought would be helpful for GPs/family doctors to ask to identify bipolar symptoms when people presented with low mood or other mental health difficulties. These ideas are listed below on the left.

Please indicate in the two columns below 1) which you think would be helpful questions for GPs to ask, and 2) whether you have experienced any questions like this being asked by GPs/family doctors in primary care.

	1) Useful for GPs to ask	2) I was asked something like this by a GP
a. Have you ever experienced an unusually high mood before?	<input type="checkbox"/>	<input type="checkbox"/>
b. Have you noticed any changes in your mood recently, and has it affected your sleeping/eating/social relationships? (e.g. a general exploration of how things are)	<input type="checkbox"/>	<input type="checkbox"/>
c. What did you do yesterday/this week? Then what? What time did you go to bed? (e.g. just asking about daily activities to detect anything out of the ordinary)	<input type="checkbox"/>	<input type="checkbox"/>
d. When did you last feel happy? What were you doing? (e.g. asking about periods of happiness to see if anything was more extreme than typical experiences of happiness)	<input type="checkbox"/>	<input type="checkbox"/>
e. 1) I don't think any of the above would be useful 2) I wasn't asked any of these	<input type="checkbox"/>	<input type="checkbox"/>

22. Do you have any other ideas about the most useful questions GPs could ask to help them identify whether someone has bipolar disorder? *(Optional)*

Value and usefulness of having a diagnosis

23. Do you think that bipolar disorder is now the correct diagnosis for you?

☐ Yes ☐ No

24.

a. Has receiving a diagnosis of bipolar been **helpful** to you in any of the following ways?

(please note, this question and 24.b are not about the advantages/disadvantages of bipolar)

experiences and symptoms, but are about the helpfulness/unhelpfulness of being given a diagnosis itself).

(select all that apply)

- ☐ It has helped me to make sense of my experiences and symptoms
- ☐ It has helped me to find out more about the condition
- ☐ It has opened up treatment choices
- ☐ It has meant that I have access to the right medication
- ☐ I have access to help and support I may not have had access to before (e.g. social, financial)
- ☐ It has meant that work are more supportive and I get certain allowances
- ☐ It has meant that I can't be discriminated against at work
- ☐ It has helped other people to understand me better
- ☐ It has been associated with public figures who are admired, so people respect me too
- ☐ It has made me feel proud that I can cope with a difficult condition
- ☐ It has given me insight into the condition, which has helped me to manage it better now
- ☐ None of the above
- ☐ Other *(please specify)*:

b. Has receiving a diagnosis of bipolar been **unhelpful** to you in any of the following ways?

(select all that apply)

- ☐ People can judge all my behaviour in the context of the disorder -- e.g. I am not allowed to have normal up and down days like everybody else
- ☐ The social stigma of having a diagnosed mental health problem can be difficult to deal with
- ☐ I am worried about how other people will react if I tell them I have bipolar
- ☐ It can be self-handicapping, and stop me from thinking I can do things
- ☐ It has meant that I am reliant on medication
- ☐ It can be disempowering
- ☐ It can make me question my own identity
- ☐ It can feel like a life sentence rather than something which I could completely recover from
- ☐ It can mean I live up to what's expected of someone with this diagnosis -- self-fulfilling prophesy
- ☐ It can affect my self-esteem and how I feel about myself
- ☐ It can mean that it is more difficult for me to fit in with peers, friends and colleagues who know that I have this
- ☐ None of the above
- ☐ Other *(please specify)*:

c. Considering the options you have thought about in 24a and 24b, would you rather have a diagnosis of bipolar, or no diagnosis at all?

(NB this question is not about whether you would rather or not have all the the symptoms and

experiences associated with bipolar disorder, but whether you would rather/rather not have the diagnostic label)

- ☐ I would "prefer" to have a diagnosis of bipolar disorder to explain my experiences than no diagnosis at all
- ☐ I would "prefer not" to have this diagnosis
- ☐ I'm undecided

25. Do you have any other questions, comments or thoughts about any of the issues raised in this survey? *(Optional)*



This is the end of the survey.

Please note that when you click the continue button your completed survey will be submitted.

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Service User Views and Experiences of Diagnosis In Bipolar Disorder

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Survey complete!

Thank you very much for taking part in our research! Your answers are now submitted.

If you have any questions or queries about the project, please contact:

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Appendix D – Focus group information sheet

Exploring Service User Views and Experiences of Diagnosis in Bipolar Disorder

Focus Group – Participant Information Sheet (Version 3)

We would like to invite you to take part in our research study about bipolar disorder diagnosis. Please read the following information to help you understand what the study is about and what it will involve before you decide whether or not to take part.

What is the purpose of this study?

Research has shown that people can wait a long time between experiencing bipolar mood symptoms and being properly diagnosed. Some researchers have found that bipolar disorder may be over-looked or not recognised by GPs and healthcare professionals. This could mean that people are not offered the most suitable treatment and may face more problems in the long run. Whilst a lot of research has been carried out in this area, service users are not often asked what they think. The purpose of this study is to ask people experiencing bipolar disorder, as well as their family members or carers, what they think about this issue, and to explore their ideas on what can be done to improve this situation. This may give us useful information on how to improve services for people with bipolar disorder.

Why have I been asked to take part?

We are looking for people who have a diagnosis of bipolar disorder, or who are a family member or carer of someone with bipolar disorder, to take part in a focus group. As a member of Bipolar UK, we are very interested in your opinions and experience of diagnostic issues in bipolar disorder and would like to invite you to take part in this group.

Do I have to take part?

No, it is entirely up to you whether you take part or not. If you do decide to take part we will ask you to sign a consent form, and give you a copy of this information sheet and the consent form to keep. If you initially decide to take part and then change your mind, you are free to withdraw at any time without a reason and if you prefer, we will not use any of the information you have provided (up until the point focus group information is anonymously transcribed, when we will no longer know which is your data)

What will I be asked to do if I take part?

If you agree to participate, we will invite you to attend a focus group up to six other participants. A focus group involves a researcher getting together a small group of people to have a discussion about particular topics. There will be specific questions that the researcher wants to ask, but the discussion will be flexible and people will be encouraged to

Speak out about relevant issues that they think are important (for example, ideas on health care professionals' approach to diagnosis). The focus group will last about two hours, but there will be time for a break in the middle. It will be audio recorded in order to help the researcher remember everything that has been said. These audio recordings will be transcribed within one month of the focus group and anonymised. The original recordings will then be destroyed.

It will be held:

At: Chapter Arts Centre, Market Road, Cardiff, CF5 1QE.

In: Meeting Room 2

On: 27th October 2012 Time: 6 – 8pm

Following discussions with and advice from the group, an internet survey will be designed, with the aim of asking a much larger number of people for their views on diagnosis in bipolar disorder. If you attend the focus group you will also be asked to check and try out the survey before it is available to everybody, and given the opportunity to feedback your comments by email or phone.

What are the possible disadvantages of taking part?

We do not anticipate any major disadvantages to taking part. However, you will be asked to give up a few hours of your time. There is also a possibility that talking about bipolar disorder may become distressing for a few people. If this happens to you, you can leave the group at any time and have the opportunity to talk through your difficulties with the researcher at the end. You will also be signposted to appropriate services and charities if necessary.

What are the possible benefits of taking part?

Although the study may not help you personally, the information we get from this study may help improve the treatment of other people with bipolar disorder in the future. We would also like to thank you for your time by offering you a £20 shopping voucher. Your travel expenses will also be fully reimbursed.

Will the information I give you be kept confidential?

All of the information that is collected about you during the focus group will be kept strictly confidential. The discussion will be audio recorded, so it may be possible for the researcher to identify who has said what during the group. However, only the researcher and the two project supervisors will have access to the audio recordings. The audio recording will be transcribed, but all comments will be anonymised. Themes identified during the focus group discussions will be used to help us design a survey. However, nothing will be connected directly with your name or any other personally identifying information. All data will be stored securely at Archway House (NHS clinical psychology training department).

What happens after the focus groups and after the project finishes?

After the focus groups, an internet survey will be conducted in order to ask a greater number of people their views on diagnostic issues with bipolar disorder. You will be invited to check through and comment on this survey before it is available online. Once the survey is

finalised, it will be available for two months for people to complete. There will be another information sheet and consent form online for this. It is hoped that 200 to 400 people will complete the survey. After two months, the survey will be removed and the results will be analysed and written up as part of a Doctorate in Clinical Psychology thesis. Results may later be published in research journals. A summary of study findings will be fed back to participants via Bipolar UK.

Who is carrying out, organising and funding the research?

This study is being carried out by Naomi Swift (Trainee Clinical Psychologist) as part of a doctoral thesis funded by the NHS and accredited by Cardiff University. The project is being supervised by Dr Daniel Smith (Consultant Psychiatrist) and Professor Neil Frude (Consultant Clinical Psychologist). Dr Smith is part of the Cardiff University Mood Disorders Research Group.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Cardiff University School of Psychology Research Ethics Committee.

Further information and contact details

Thank you for taking the time to read this information sheet. If you have any questions or queries about the project, please contact:

Naomi Swift, Trainee Clinical Psychologist : 07530 467600

Professor Neil Frude, Consultant Clinical Psychologist : 02920 206464

Dr Daniel Smith, Consultant Psychiatrist : 02920 743871

Appendix E – Focus group consent form

Consent Form

Title of Project: Exploring Service User Views and Experiences of Diagnosis in Bipolar Disorder

Name of Researcher: Naomi Swift

If you have read the information sheet and are happy to take part, please complete and sign the following consent slip.

Please tick box

I confirm that I am over 18 years of age.

☐

I confirm that I have read and understand the information sheet (Version 3) for the above study.

☐

I consent to my participation in a focus group being audio recorded.

☐

I understand that my participation is voluntary and that I am free to withdraw at anytime up until the audio recordings are transcribed without giving any reason.

☐

I consent to taking part in the study.

☐

Name _____

Signature _____

Date _____

Appendix F – Survey information page

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Service User Views and Experiences of Diagnosis In Bipolar Disorder

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Welcome

Survey Participant Information Page

We would like to invite you to take part in our research survey about bipolar disorder diagnosis. Please read the following information to help you understand what the project is about and what it will involve before you decide whether or not to take part.

What is the purpose of this study?

Research has shown that people can wait a long time between experiencing bipolar mood symptoms and being accurately diagnosed. Some researchers have found that bipolar disorder may be over-looked or not recognised by GPs and healthcare professionals. This could mean that people are not offered the most suitable treatment and may face more problems in the long run. Whilst a lot of research has been carried out in this area, service users are not often asked what they think. This survey has been designed with the help of a service user focus group in order to ask other service users about the most important issues and their views on what can be done to improve things. This may give us useful information on how to improve services for people with bipolar disorder.

Why have I been asked to take part?

We are looking for 200-400 people who have a diagnosis of bipolar disorder, or who are a family member or carer of someone with bipolar disorder (see separate link), to complete an online survey. We have publicised this survey through the charity Bipolar UK. As someone who accesses this organisation, your opinions and experiences of diagnostic issues in bipolar disorder are of special interest to us and we would like to invite you to complete this survey.

If you do not have a diagnosis of bipolar disorder then please do not complete this survey.

Do I have to take part?

No, it is entirely up to you whether you choose to complete the survey. If you initially decide to take part and then change your mind, you are free to withdraw at any time without a reason and, if you prefer, we will not use any of the information you have provided up to that point. In this case, please let the researcher know in the comments box for the final question of the survey (Question 25) or by contacting them (details below) with the date and time you began the survey and the number of questions you've already completed so that your specific data can be deleted.

What will I be asked to do if I take part?

If you agree to participate, we will ask you to give your consent on the next page, then you can continue on with the survey. It consists of 25 questions on your views about diagnostic issues in bipolar disorder. Some questions will be about your personal experiences. Most questions are multiple choice, but you will be given the opportunity to add your own comments and space to add general comments at the end. The survey will typically take 30 minutes to complete.

What are the possible disadvantages of taking part?

We do not anticipate any major disadvantages to taking part. However, you will be asked to give up about 30 minutes of your time. You will also be asked questions about topics which are personal to you. If this causes you any distress, you will be able to contact the researcher to discuss this further (details at the end of this page), and signposted to helping organisations.

What are the possible benefits of taking part?

Although the study may not help you personally, the information we get from this study may help improve the treatment of other people with bipolar disorder in the future.

Will the answers I give be kept confidential and what will happen to my data?

You will not be asked to provide your name during this survey, so all of the answers which you give will be anonymous, meaning that they cannot be traced back to you personally. Personal data stored by your web browser (cookies), which could be used to track an anonymous survey back to a respondent, are also not stored by this survey software, further protecting your identity. After you have completed the survey, the data will be controlled by Cardiff University. All data collected will also be held securely by the survey software provider (Bristol University) under contract and then retained by Cardiff University in Accordance with the Data Protection Act (1998). Data from the survey, including answers to questions where personal information is requested, will only be used by the researcher for the purposes of this research project.

What happens next?

The survey will be available online for two months. After this, the survey will be removed and the results will be analysed and written up as part of a Doctorate in Clinical Psychology thesis. Results may later be published in research journals. A summary of study findings will be fed back to participants via the Bipolar UK website or publications.

Who is carrying out, organising and funding the research?

This research is being carried out by Naomi Swift (Trainee Clinical Psychologist) as part of a doctoral project funded by the NHS and accredited by Cardiff University. The project is being supervised by Dr Daniel Smith (Consultant Psychiatrist) and Professor Neil Frude (Consultant Clinical Psychologist). Dr Smith is part of the Cardiff University Mood Disorders Research Group.

Who has reviewed the study?

All research is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Cardiff University School of Psychology Research Ethics Committee.

Further information and contact details

Thank you for taking the time to read this information. If you have any questions or queries about the project, please contact:

Naomi Swift, Trainee Clinical Psychologist : 07530 467600, Email: SwiftN@Cardiff.ac.uk
Professor Neil Frude, Consultant Clinical Psychologist : 02920 206464
Dr Daniel Smith, Consultant Psychiatrist : 02920 743871

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Appendix G – Survey consent page

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Service User Views and Experiences of Diagnosis In Bipolar Disorder

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Consent Page

If you have read the information provided on the previous page and are happy to take part, please check the following boxes.

<p>1.</p> <p>a. I confirm that I am over 18 years of age.</p> <p><input type="radio"/> Yes <input type="radio"/> No</p> <hr/> <p>b. I confirm that I have read and understand the information provided about the following survey.</p> <p><input type="radio"/> Yes <input type="radio"/> No</p> <hr/> <p>c. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving any reason.</p> <p><input type="radio"/> Yes <input type="radio"/> No</p> <hr/> <p>d. I consent to taking part in the study.</p> <p><input type="radio"/> Yes <input type="radio"/> No</p> <hr/>
--

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Survey testing only

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Appendix H – Focus group demographic questionnaire

Appendix H - Focus group participant demographic questionnaire – 27/10/11

Participant Initials: _____ Age: _____ Date of Birth: _____

For each of the questions below, please circle or tick the option that best describes you.

1. Ethnicity

British

- Welsh
- English
- Scottish
- Northern Irish

Irish

European

Caribbean

African

Any Asian

Any other ethnic group

2. Employment Status

Employed full-time

Employed part-time

Self-employed

Housewife/husband

Volunteer work

Student

Unemployed

Retired

3. Highest education

O-Levels/GCSEs

A-Levels

GNVQ or other vocational qualifications

University Degree

Post-graduate Degree

None of the above

4. Do you know the name of the diagnosis have you been given?

Bipolar I

Bipolar II

Other – please state:

5. When were you first given this diagnosis?

Month:

Year:

Appendix I – Survey publicity material

Appendix I – Survey publicity material (Sent out via email by Bipolar UK)

Do you have a diagnosis of bipolar disorder, or live with/care for someone with bipolar disorder?

Do you have any views on the process of being diagnosed?

We are carrying out some research based at Cardiff University looking at people's experiences of receiving a diagnosis of bipolar disorder. We are interested in your opinions on the value of diagnosis, how long this process can take, and how it could be improved. We are also very interested in carers' or family views on someone close receiving a bipolar diagnosis. We hope that research into this may improve the assessment and care of people with bipolar disorder in the future.

If you are interested in sharing your views and experiences by completing an online survey, please access the following internet links.

***SERVICE USERS* - If you have a diagnosis of bipolar disorder yourself please go to:**

<https://www.surveys.cardiff.ac.uk/bipolardiagnosis>

***CARERS* - If you live with or care for someone with a diagnosis of bipolar disorder please go to:**

<https://www.surveys.cardiff.ac.uk/bipolarcarer>

If you would like more information about this research, please contact Naomi Swift on 07530 467600 or SwiftN@Cardiff.ac.uk.

**Appendix J – Cardiff University School of Psychology Research
Ethics Committee approval**

Appendix J – Cardiff University School of Psychology Ethics Committee approval email

Re: Ethics feedback - EC.11.07.05.2832RR

LSRP



Tue, Jul 19, 2011 at 9:36 AM

psychethics

<psychethics@cardiff.ac.uk>

To: swift@cardiff.ac.uk

Cc: Neil.Frude@cardiffandvale.wales.nhs.uk

[Reply](#) | [Reply to all](#) | [Forward](#) | [Print](#) | [Delete](#) | [Show original](#)

Dear Naomi,

The Ethics Committee has considered your further revised postgraduate project proposal: Exploring service user views and experiences of diagnosis in bipolar disorder (EC.11.07.05.2832RR).

The amended project has now been approved.

Please note that if any changes are made to the above proposal then you must notify the Ethics Committee.

Regards,

Dominique Mortlock

School of Psychology Research Ethics Committee
Tower Building
Park Place
CARDIFF
CF10 3AT

Ffôn /Telephone: +44 (0) 29 2087 0360

Ffacs/Fax: +44 (0) 29 2087 4858

<http://psych.cf.ac.uk/aboutus/ethics.html>

**Appendix K - Cardiff and Vale University LHB Research and
Development approval**



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

10 August 2011

Miss Naomi Swift
South Wales Doctoral Programme in
Clinical Psychology
Archway House, 77 Ty Glas Road
Llanishen
Cardiff
CF14 5DX

Dear Miss Swift

**Project ID : 11/MEH/5130 : Exploring Service User Views And Experiences Of
Diagnosis In Bipolar Disorder**

Further to recent correspondence regarding the above project, I am now happy to confirm receipt of:

- Evidence of favourable opinion from the School of Psychology Research Ethics Committee.
- Revised documentation as required by the REC in order to obtain favourable opinion

The following amended documentation is approved for use with this study:

Document	Version	Date
Protocol and appendices A-K	SAPNJS1	Revised 18/07/11

Please accept this letter as confirmation of sponsorship by Cardiff and Vale UHB and permission for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D Office if any external or additional funding is awarded for this project in the future
- Inform the R&D Office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D Office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act, 2004 (for further information please contact Sharon Orton, HTA Coordinator OrtonS@cf.ac.uk).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,



Professor Jonathan I Bisson
Cardiff and Vale University Local Health Board R&D Director

CC R&D Lead, Professor Nick Craddock

Appendix L – Participant feedback on survey

Appendix L – Participant feedback

Feedback on survey in response to Q25 – Service users
Thanks. All the best.
A number of the questions presume GP contact prior to diagnosis, difficult to answer some of the qs eg my GP didn't ask this, but it was never presented to him.
Although some of the questions were difficult to answer in my case and I would have reworded them, I think the survey is a very useful exercise. Well done to the team who designed it.
Good survey and asks some interesting questions. I would like to be notified when the results are available please.
Good survey; quite happy to enter into further surveys. Bipolar seems to be a diagnosis in "fashion".
Great survey - i think one big problem is that a lot of healthcare professionals seem to have a very 'black and white' view of bipolar disorder and fail to recognise the more subtle symptoms.
I am glad that I took part in this survey.
Thank you this has been enlightening to me.
I found the form quite long, so unusually, I don't have any further comments!
Thanks for your research. I hope it helps people w Bipolar receive treatment earlier in their lives!!!!
Hope my contribution helps - I wasn't able to complete my own PhD.....
I think the survey has been extremely well thought out.
I think this is an excellent survey and the questions are really good and its one of the best surveys I have ever done. I hope it helps in some way and I wish I could tell you more. It would be great if there was more opportunities like this and even more interviews face to face to get as much information from people and therefore gain a greater understanding of mental health problems. Thanks
It has been clarifying to myself to answer your questions. Thank you
It is hard to read with racing thoughts but I did my best!
Some of the layout I found hard to follow, but interesting and important topic.
Thank you for helping to research this condition
Thank you for the work that you do. The two biggest hurdles after things became acute were the lack of awareness of GPs and the lack of time on a GPs visit to work towards a diagnosis.
Thank you for this work.
Thanks for this opportunity to contribute.
THANKYOU for this survey and to all involved. THANKING YOU VERY MUCH.
The questions in this survey were really well put together, made me think a lot about my experiences of having bipolar and made me realize that a lot of my most difficult experiences in life before diagnosis could have been avoided/managed better if I had had the right diagnosis, treatment and support.
This is a very good survey. It has given me the opportunity to consider my condition.
This is an excellent direction to be going in and should prove extremely helpful if it results in wider education about bipolar to GPs and other professionals, not to mention family and the public. My husband is brilliant on the subject, such a good and empowering carer (don't like the word carer) but my parents/siblings reject the term and stigmatize me as

"different" in a bad way.
Very interesting survey. But it is hard to remember what antidepressants I was given, if any 25 years ago! Thank you for an interesting survey and best wishes for your research
Very well thought out questions that i believe if taken up, will stop people having a miserable 16 years of not knowing what was wrong like myself. Well done!
Very worthwhile piece of research.
Wow! Good. Some of the early questions are too prescriptive asking for figures and it is hard to always be accurate. Happy to help and want to find out what the results are. Good to remember where I have come from and celebrate success. I remain aware and will not be complacent!
Yes, thanks.

Feedback on survey in response to Q25 – Carers
A lot of this is hard to remember as we have lived with it for over 20 years. However any thing that helps improve the situation for other people is worth researching.
A well thought-through questionnaire which I hope will be helpful for the development of the treatment and care of bipolar. Every success.
Brilliant survey, the general public need more awareness about mental health as a whole let alone bipolar disorder
I am more than happy to support this survey. So much more is needed to support the diagnosis and give productive support to the user and their families.
it didn't care about me as a carer... was diagnosis helpful, do I feel ashamed, do I notice symptoms etc
I am pleased to be able to help with this survey, I don't think the carer's voice is heard enough they can provide so much valuable information but are more often than not ignored.
Keep up the work - the more people understand of the problem the better for those with the illness and their family / friends / employers.